



UNIVERSITY
OF TASMANIA

**Capacity Building and Resilience for the
Community-Based Dementia Care Workforce**

by

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A report submitted in fulfilment of the requirements for the degree of Doctor of
Philosophy (Psychology) at the University of Tasmania.

November, 2012.

Statements and Declarations

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I certify that this thesis contains no material which has been accepted for a degree or diploma by the University of Tasmania or any other institution, except by way of background information where acknowledgement has been made in the text of the thesis, and that to the best of my knowledge and belief this thesis contains no material previously published or written by another person except where due acknowledgement has been made in the text of the thesis.

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Abstract

Projected increases in dementia prevalence worldwide have focused attention on the need to build capacity to support the workforce in order to avert formal care shortages. Dementia care is characterised by a low qualified workforce with low levels of recruitment and retention. The thesis expands the view of workforce capacity building, from a focus on knowledge and skills, to include adjustment to work roles and coping in the face of high job demands. This approach will inform the design of effective interventions and quality of training to develop and retain dementia care workers. Understanding aspects of worker resilience will help define ways to enhance the capacity of workers with low qualifications.

The series of studies explored different aspects of capacity building, applying theories from organisational, clinical and social psychology to offer a multi-disciplinary approach. The *job-demands and resources model*, *self-efficacy* and *communion* were concepts applied to the experience of community-based dementia care workers. Study One compared the effectiveness of dementia training interventions for both workforce and organisational climate variables, in a systematic review of the most rigorous research. Study Two used a mixed methods design and described community-based dementia care workers' resilience and vocational experiences. Workers' job roles, training, employer agenda, organisational support and commitment to work were investigated. While Study Two examined the workforce, Study Three explored informal dementia carers' experience of present and future community-based service delivery, and followed a mixed methods design. The findings informed recommendations for service providers to improve capacity for workers and organisations.

Collectively, the results identified variables relevant for capacity building intervention research and health service delivery. There was a consensus between paid workers and informal carers that improvements in community dementia awareness, workforce, and organisational systems would reform future dementia care services. Specifically, dementia knowledge and stress management were areas consistently identified as ways to improve worker skills and capabilities. Whereas, organisational factors such as, better employment conditions, collaboration, and quality supervision were identified to improve worker commitment and performance. Intrapersonal factors that formed a resilient profile of adjustment were found to be essential for coping with high job demands at work. A sense of belonging based in social connectedness at work typified this experience and was proposed as a core construct, called *occupational communion*. A conceptual model was presented where occupational communion mediated the effects of job demands on capacity building and resilience.

The thesis expanded the view of capacity building to include both intrapersonal coping and organisational factors to enhance worker development and resilience. In this way, the findings of the thesis offer a significant contribution to workforce capacity building for health and dementia care services. Future health care practice that recognises and aims to enhance occupational communion is needed, in order to attract and retain workers, and improve care for people with dementia.

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Statement of Co-Authorship

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Candidate was the primary author and led the formulation of research questions with author 2 which were reviewed and refined by all authors. The candidate analysed the data and led the manuscript preparation, to which all authors contributed.

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Title: *The power of ‘occupational communion’ for the community-based dementia care workforce: a key finding from the Work 4 Dementia Project*

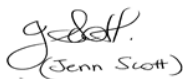
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Publications and Awards

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Publications related to thesis

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Introduction

One-hundred-and-six years ago Alois, Alzheimer presented the first case of a distinctive neurodegenerative disorder to his medical colleagues, which was later named Alzheimer's disease (Alzheimer's Disease International, 2012). Since the first discovery, research into the symptoms, causes, risk factors, and treatment of Alzheimer's disease and other dementias has expanded (United States Alzheimer's Association, 2012). Despite the fact that this disease was identified over 100 years ago, research developments in biology, epigenetics, pharmacotherapy and psychosocial intervention has gained momentum only in the past 30 years (USAA, 2012). A cure still remains elusive and the precise physiological changes that trigger the development of Alzheimer's disease remain mostly unknown (USAA, 2012). In addition, many translational challenges exist regarding the application of psychosocial intervention research to the practice setting (Draper, Low, Withall, Vickland, & Ward, 2009).

A small number of countries around the world agree that much still needs to be done to provide adequate care to people with Alzheimer's disease and other dementias, particularly in light of the ageing population (Benbow & Kingston, 2010). In a recent report authored by two peak bodies, the World Health Organisation (WHO) and Alzheimer's Disease International (ADI), dementia was named as an international public health priority (WHO & ADI, 2012). Currently there is a lack of international preparation to manage this priority, with as little as 6% of the WHO's member states possessing a detailed action plan on dementia (WHO & ADI, 2012). In the report, the WHO and ADI strongly advocate and encourage country preparedness strategies that improve Alzheimer's care. Workforce capacity building was raised as a main issue suggesting key issues relate

to staff competencies, training and collaboration (WHO & ADI, 2012). While some specific country examples and broader suggestions are made in the substantial report by the WHO and ADI, what remains missing is a systematic examination of the extent of, and evidence for, interventions to enhance capacity and workforce preparedness.

Aims of the current investigation

The public health priority of dementia is an international dilemma. This thesis focuses on the Australian context of dementia care in the current pre-dementia-epidemic environment, where there is still potential for aged care reform. An investigation of preparedness and capacity to strengthen Australian dementia care support services is conducted and parallels are made with the international arena. This thesis presents eight chapters that collectively examine ways to improve service delivery for people with dementia, in order to provide recommendations that contribute to innovative strategies for capacity building in dementia care. The aim of the thesis is to broaden the understanding of capacity building for dementia care workers, from a focus on knowledge and skills, to include adjustment to work roles and coping in the face of high job demands. This aim will be explored by a series of three separate studies, Study 1, Study 2 - Part A and Part B, and Study 3. Ultimately, it is envisaged that the results will inform ways to improve organisational preparedness for the ageing population.

In Chapter One, the background issues to capacity building in dementia care are presented in an appraisal of the nature of the ageing population and dementia care services. In Chapter Two, the characteristics inherent in the international dementia care workforces including issues such as staff retention, recruitment, job satisfaction and well-being are discussed. Chapter Three will introduce the

theoretical frameworks that underpin capacity building from a unique tri-theoretical approach, closely reviewing concepts from *organisational*, *clinical* and *social psychology*. Organisational theories such as the *job-demands and resources* model (Demerouti, Bakker, Nachreiner, & Schaufeli, 2001), *perceived organisational support* theory (Eisenberger, Huntington, Hutchison, & Sowa, 1986) and *person-organisation fit* theory (Kristof, 1996) offer strong explanations of human resource factors (i.e., burnout, retention and organisational commitment) in the administration and general health setting (Darr & Johns, 2008). Clinical psychological coping resources of *role ambiguity* (Kahn, Wolfe, Quinn, Snoek, & Rosenthal, 1964), *emotional labour* (Hochschild, 1983) and *self-efficacy* (Bandura & Adams, 1977) are also described to account for the intrapersonal psychological factors inherent during learning and skill acquisition that can be applied to the training sphere. The social psychological concept of *communion* (Bakan, 1966) is also introduced with relevance for the inherent social nature of work for community-based care workers. Whether these theories are relevant for the dementia care setting, where workers have low levels of education and training to deal with the multi-faceted and complex care needs of people with dementia will be also explored. A tri-theoretical approach will expand the understanding of capacity building and may offer innovation for dementia care. A final subsection of Chapter Three will briefly outline the methodological and ethical considerations of the research approach.

While Chapters One, Two and Three will describe the Australian context of dementia care and theoretical frameworks for strengthening support services, Chapters Four, Five, Six and Seven will present a series of studies that investigate factors that inform capacity building. Chapter Eight will integrate the overall

findings from the series of studies and present recommendations to inform dementia care service delivery. While the studies in the thesis follow separate methodologies, they are closely connected. The studies are connected as they collectively aim to broaden the view of capacity building to include employee coping and adjustment to work roles. Specifically, each study offers a unique contribution in a defined research area, within capacity building.

Chapter Four will present the results of Study 1 that investigated the current level of evidence for dementia training interventions. The characteristics of dementia care workforces are described in Chapter Two, with particular reference to Australian and international workforce qualifications and training. The literature outlined in this section of the thesis is intended to provide a background for Study 1 and dementia training. Study 1 extended the understanding of capacity building, beyond a dementia training focus on workforce knowledge and skill. A comprehensive approach was taken to the examination of training interventions for workers in the dementia care setting, acknowledging the bi-directional relationship between workforce variables (i.e., well-being, job satisfaction) and organisational climate (i.e., productivity, capacity at the level of the workplace) that are inherent in capacity building (Rafferty & Griffin, 2004). An investigation with this focus will help inform knowledge about the processes that are essential to this interaction. Study 1 followed the methodology of a systematic literature review to present the most rigorous intervention studies to inform service providers on best approaches, informed by scientific principles, to train and retain the dementia care workforce.

Chapter Five will describe Study 2 - Part A, which is a qualitative investigation of a community-based dementia care workforce. A focus on

community-based dementia care is considered of high importance due to the trend for “ageing in place” and subsequent change in need for services that are based in the personal domain of care recipients’ homes. A full description of dementia care services is provided in Chapter One with a subsection on community care, with relevance for services in Australia and internationally. This information is partly intended to provide a background and context for Study 2. The results of Study 2 - Part A identified and discussed the concept of *occupational communion* informed by the social psychology theory of communion and agency (Bakan, 1966). Occupational communion was found to exist at the interface between social and organisational psychology theories and may act as a coping resource. Study 2 - Part A described the connections between the theories highlighted in Chapter Three with particular relevance for a community-based dementia care workforce. Qualitative themes identified in Study 2 – Part A informed intervention components relevant for capacity building in dementia care. These findings broadened the approach to capacity building by focusing on the importance of social connectedness in care work.

Chapter Six will describe an extension of Study 2 – Part A, namely Study 2 - Part B, which is an examination of the intrapersonal coping and occupational demands and resources experienced by the same community-based dementia care workforce. Reviewing the data in this way extended the view of capacity building, to include employee coping and adjustment to work roles. Study 2 - Part B employed a case-based clinical psychology approach to explain profiles of worker adjustment to job demands. Profiles showed factors that contribute to resilience and distress in workers. The literature presented in Chapter Two, in particular the subsection on staff well-being and satisfaction has strong relevance for Study 2 –

Part B. Such patterns of adjustment identified by the profiles, informed capacity building by highlighting potential areas for intervention to aid workforce development. Quantitative results were analysed in light of qualitative themes to produce converging evidence that will inform the development and structure of capacity building interventions applicable to the Australian community-based context.

Chapter Seven will describe results from Study 3 which is a mixed methods (i.e., qualitative and quantitative data) study that describes informal dementia carers' perspectives on service delivery and the future agenda of the sector. Informal carers' needs are described in a subsection of Chapter One, which focuses on population ageing and dementia care. This summary of the literature on dementia carers' is particularly relevant for Study 3. While the aim of Study 3 was to describe in detail the informal carers' perspective, qualitative themes identified by informal carers were compared to qualitative themes identified by formal care workers from Study 2 - Part A. An objective was to examine the level of satisfaction informal carers had with services (quantitative data). The comparison of themes for both carer types determine the extent of alignment between the informal and formal spheres, to further inform level of preparedness for future demands. Informal carers are the receivers of support services and play an important role in co-ordinating support for the person with dementia. Study 3 broadens the view of capacity building for dementia care by reviewing informal carers' perspectives on service delivery. Informal carers experience the outcomes of capacity building strategies (i.e., improvement in service delivery and workers' skills) and therefore, had a valuable voice to offer in the determination of intervention success. Further, collaboration with informal carers may assist in

determining a coproduced message, where informal carers' knowledge and experience are valued, lending to good face validity and likely acceptance of innovation and service delivery change.

Chapter Eight is an overall discussion of the research and translation implications of the series of studies in the thesis. A summary and integration of the results from the studies is presented and the strengths are discussed. In this final section of the thesis, a list of recommendations is provided that relate to the findings of the studies and the reviewed literature. It is envisaged that by providing recommendations, future research may be improved and service providers can be informed of innovative capacity building approaches for dementia care.

Conclusion

The thesis will utilise a bottom-up organisational approach to develop a synthesis of ideas and recommendations about capacity building in dementia care. Adopting a close inspection of phenomenon at the “coal face” of dementia care will serve to supply detailed information to one end of the dichotomy of innovation change, where practical strategies founded in social scientific inquiry will be pertinent to the dementia care setting. While some suggestions for innovation implementation will be made regarding the translation of strategies from evidence-based research to the workplace setting, the top-down or managerial perspective (the other end of the dichotomy) will not be described here. Duly, the purpose of the thesis is to collate a body of work that informs the likely acceptance of the workforce to take on additional roles and cope with increases in demands. By examining the current condition of dementia care, a start can be made to determine service preparedness and potential for capacity building.

Overall, the aim of the thesis is to broaden the understanding of capacity building for dementia care. The thesis will collectively examine ways to improve service delivery for people with dementia, with the objective to provide recommendations that contribute to innovative strategies for capacity building for dementia care. In light of the current economic climate, identifying strategies to prepare dementia care services that are sustainable and sensitive to limited resources will promote progressive societal adjustment to the ageing population.

Chapter 1

Population Ageing and Dementia Care

“In the current fiscal environment, we must be vigilant in ensuring that the provision of social protection, long-term care and access to public health for the elderly is not undermined...”.

A comment made by Ban Ki-moon, Secretary-General of the United Nations,
Message for International Day of Older Persons (2011, para. 1).

The Nature of the Ageing Population

Population growth around the world has reached a pivotal moment in human history, with people over 60 years of age soon to outnumber children (Carstensen, 2008). Population ageing is one of the most distinctive demographic events of the 20th century with virtually all countries experiencing population ageing with varying levels of intensity over different time frames (United Nations; UN, 2002). The young-old balance is shifting throughout the world. Population ageing is defined by the United Nations (2002) as “the process by which older individuals become a proportionally larger share of the total population” (p. 1). The demographic transition is caused by a decline in fertility rates paralleled by decline in mortality rates, particularly during older ages. There are some differences in the young-old balance between developed and less developed regions. In more developed regions the change in fertility rates means that there are less children per older persons. In fact the proportion of older people currently exceeds children, which is expected to double by 2050 (UN, 2002). A similar pattern exists for less developed regions. However, the fertility rates are not as substantially low in less developed regions compared to the more developed regions. In less developed regions recent age-distribution changes have been slow, but will accelerate over the next half of the century (UN, 2002).

Population ageing is unprecedented, pervasive, enduring and has profound implications for many facets of human life. The 21st century is set to experience more rapid ageing than any century before it, with the pace of change differing greatly for each country, with countries that started the process later having less time to adjust (UN, 2002). The enduring nature of population ageing means that there will not be a return to the young populations that have characterised the

recent past. There are both social and economic implications on society, from changes to the long-term viability of intergenerational social support systems and family structure (Cliquet & Nizamuddin, 1999) and social welfare systems that support retirement or pension payments over longer periods of time.

The *old age-dependency ratio* measures the number of older persons as a share of those of working age and is defined as the ratio between the (projected) total number of elderly persons (aged 65 and over) and the (projected) number of persons of working age (from 15 to 64; Eurostat, 2008). Continued increases in longevity will ensure that the old-age dependency ratio will rise sharply over the next 40 years, with the United Kingdom expected to rise from 1:4 in 2010, to 1:2.4 in 2060 (European Commission; EUC, 2010). An increase in the old-age dependency ratio indicates a situation in which an increasing number of potential beneficiaries of health and pension funds are supported by a relatively smaller number of potential contributors (UN, 2002). For societies to account for the discrepancy, those who are economically active are likely to face high financial demands through bearing the burden of tax and other conditions such as increases in health care insurance premiums. Social support and welfare systems will also need to undergo substantial change in order to remain effective and sustainable in the face of population ageing.

In 2000, the proportion of people aged above 65 years in the United States of America was 12% (US Census Bureau; USCB, 2009). By 2050, it is projected to be 21%. Australia's population follows the same trend. Currently around 13% of the Australian population is over the age of 65 (Australian Bureau of Statistics; ABS, 2008a). However, by 2056 the percentage is projected to be between 23 to 25%. While the numbers of older people increase, change is also present in certain

categories within the elderly population, with the 80 years or over age group growing faster worldwide than any younger segment of the older population (regardless of their geographic location or country development stage; UN, 2002). In the future most older adults above 80 years will be located in less developed regions (57% by 2025 and more than 70% by 2050) which is in contrast to the current trend that the greatest proportion of older adults (above 80 years) is located in more developed regions (UN, 2002). Sex differences are present in the oldest-old, with older women greatly outnumbering older men in most countries worldwide (UN, 2002). Despite there currently being a small number of centenarians in the world, it is estimated that by 2050 they are projected to number 3.2 million, an increase of about 18 times the current figure (UN, 2002). Most centenarians can be found in more developed countries and people living beyond 100 years of age will rise with centenarians expected to be the substantial majority (68%) of the older-old by the year 2050 (UN, 2002). Not only will social welfare systems be providing financial aid for longer, but the types of support and ways of delivering care to this proportion of the ageing population will need to expand to match the expected growth.

The predominately ageing population is likely to be associated with increases in age related disease, such as dementia. Dementia is not a normal part of ageing, although it mainly affects older people (Stephan & Brayne, 2008). Dementia is a syndrome, usually of a chronic or progressive nature, caused by a variety of brain illnesses that affect memory, thinking, behaviour and ability to perform everyday activities (WHO & ADI, 2012). In the last decade, mortality rates associated with illnesses such as Alzheimer's disease and dementia have more than doubled (ABS, 2009; Australian Institute of Health & Welfare; AIHW,

2007). Conversely, deaths attributable to other diseases such as Human immunodeficiency virus (HIV), stroke, heart disease and cancer have decreased. In the United States between 2000-2008 the proportion of deaths due to other major causes included a decrease of 29% for HIV, 20% for stroke, 13% for heart disease, 8% for prostate cancer and 3% for breast cancer (US Alzheimer's Association; USAA, 2012). Whereas the proportion of deaths due to Alzheimer's disease and other dementias increased by 66% (USAA, 2012). This places Alzheimer's disease as the fifth-leading cause of death for those aged 65 and older living in the United States. A similar case also exists for Australia where this category of illnesses has gone from being the seventh-leading cause of death in Australians to the third (ABS, 2009, 2012 – Part B). Dementia is becoming one of the highest priorities in health in the 21st century with its impact becoming greater as decades go by. It is one of the major causes of disability and dependency among older people worldwide (WHO & ADI, 2012). Thus, dementia represents a critical challenge for health care systems in Australia and internationally.

Some nations declare the necessity to find ways to support and bolster their workforce to prevail against the challenges posed by dementia in the 21st century (Australia's National Framework for Action on Dementia, 2006; Canada's Rising Tide, 2010; US Alzheimer's Study Group, 2009; England's National Dementia Strategy, 2009; Norway's Dementia Plan, 2007). For these nations preparation at a political and public policy level is underway, however for most other countries, plans on how to tackle dementia have not been developed. Countries such as Australia, Canada, England and the United States lead the way with strategic plans and statements of intent, but how these plans are monitored for success and translation of outcomes for people with dementia, their carers and family members

is rarely detailed. In addition, the research evidence and scientific inquiry informing such plans of action remain ill-referenced and lack a comprehensive approach to processes inherent in innovation and organisational change.

Epidemiology of dementia

Dementia is an overarching term used to describe a variety of diseases with common characteristics such as changes in cognition, memory and behaviour caused by abnormal function or death of nerve cells in the brain (USAA, 2012). Dementia is often diagnosed by physicians following a set of clinical criteria detailed in the Diagnostic and Statistical Manual of Mental Disorders – Text Revision, 4th edition (American Psychiatric Association; APA, 2000). For an individual to be diagnosed with dementia she or he must demonstrate a decline in memory and must also display at least one of four symptoms (that indicate a reduction of cognitive abilities that are severe enough to interfere with daily life). These include an:

- i) Ability to generate coherent speech or understand spoken or written language,
- ii) Ability to recognise or identify objects, assuming intact sensory function,
- iii) Ability to execute motor activities, assuming intact motor abilities and sensory function and comprehension of the required task,
- iv) Ability to think abstractly, make sound judgments, and plan and carry out complex tasks (USAA, 2012, p. 132).

Identifying the cause of the symptoms is also necessary, in order to discount the possibility of such symptoms (i.e., depression, delirium, thyroid problems) occurring due to another type of mental disorder (i.e., Major Depressive Episode),

or side effects of medications, which unlike dementia can be reversed with treatment (USAA, 2012).

One of the main features of dementia is the degenerative nature of the disease where symptoms are caused by irreversible damage to brain cells (USAA, 2012). Dementia is recognised as a progressive terminal illness with varied rates of disease progression, as the prognosis for a patient may range from two to over 15 years and the end-stage of the illness may last as long as two or even three years (Birch & Draper, 2008). According to the WHO and ADI (2012), the four most common subtypes of dementia in order of frequency are Alzheimer's disease (AD), vascular dementia (VaD), dementia with Lewy bodies (DLB), and frontotemporal dementia (FTD). In some patients the causes of dementia may be mixed. A person can have both abnormalities in the deposits of the protein fragment β -amyloid (plaques) and twisted strands of the protein tau (tangles) like in Alzheimer's disease, as well as brain infarcts due to small strokes blocking arteries that decrease blood flow to parts of the brain, such as in Vascular dementia (Plassman et al., 2007). Mixed pathologies are much more common than "pure" ones, particularly for Alzheimer's disease and VaD, and Alzheimer's disease and DLB (Neuropathology Group of the Medical Research Council, 2001). Other types of dementia include, Parkinson's disease, Creutzfeldt-Jacob disease, Alcohol related dementia (Korsakoff's syndrome), Huntington's disease, HIV/AIDS related dementia and normal pressure hydrocephalus (Stephan & Brayne, 2008).

Alzheimer's disease is considered to be the most common type of dementia. In the United States it accounts for 60 to 80% of cases (USAA, 2009) and in Australia for 50 to 70% of cases (AIHW, 2007). Pathological hallmarks of

Alzheimer's disease include abnormalities in the deposits of the protein fragment β -amyloid (plaques) and twisted strands of the protein tau (tangles), as well as nerve cell damage and death in the brain (USAA, 2012). Clinical symptoms include difficulty remembering names and recent events, as well as apathy and depression early in the disease course. Later development of symptoms include impaired judgment, disorientation, confusion, behaviour changes, and trouble with motor functions (i.e., walking and swallowing; USAA, 2009). Alzheimer's disease is experienced by people in different ways and people progress from mild, moderate to severe disease at varying rates. Recent clinical guidelines for diagnosing Alzheimer's disease recommended that there are three stages beginning prior to the development of symptoms. These are preclinical Alzheimer's disease, mild cognitive impairment (MCI) due to Alzheimer's disease, and dementia due to Alzheimer's disease (Jack et al., 2011). The new recommended staging will allow for early diagnosis and treatment of the disease, with hopes to slow progression as new therapies become available.

Vascular dementia refers to problems with reasoning, planning, judgment, memory and other thought processes caused by brain damage from impaired blood flow to the brain (Mayo Foundation for Medical Education and Research; MFMER, 2011). There are a number of types of vascular dementia. The two most common types are multi-infarct dementia and Binswanger's disease or subcortical vascular dementia. Multi-infarct dementia is caused by a number of small strokes, called transient ischaemic attacks (TIA), whereas Binswanger's disease is associated with stroke-related changes to the brain, caused by high blood pressure, thickening of the arteries and inadequate blood flow (Better Health Channel; BHC, 2011). The location of brain injury associated with microscopic bleeding

and blood vessel blockage influences the individual's cognitive and physical functioning (USAA, 2012). Initial symptoms of vascular dementia are more likely to include impairments in making judgements and plans rather than memory loss associated with Alzheimer's disease. Vascular dementia is less common as a sole cause of dementia than is Alzheimer's disease (USAA, 2012).

Dementia with Lewy bodies (DLB) is caused by the degeneration and death of nerve cells in the brain. The name comes from the presence of abnormal spherical structures, called Lewy bodies, which develop inside nerve cells and it is thought that these may contribute to the death of the brain cells (Alzheimer's Australia; AUAA, 2012). The Lewy bodies are abnormal aggregations of protein α -synuclein and dementia occurs when they develop in the cortex of the brain (AUAA, 2012). Three main symptoms of Dementia with Lewy bodies include visual hallucinations, parkinsonism (tremors and stiffness in muscles) and fluctuation in mental state (change from lucid to confusion and disorientation). At least two of these main symptoms must be present to meet diagnostic criteria (AUAA, 2012). Other symptoms include difficulties with concentration and attention, confusion, judging distances (often resulting in falls), depression and delusions (AUAA, 2012). Dementia with Lewy bodies has some symptoms that are common to Alzheimer's disease, but a person with Dementia with Lewy bodies is more likely than a person with Alzheimer's disease to have early symptoms of sleep disturbance, visual hallucinations and muscle rigidity (AUAA, 2012).

Frontotemporal dementia (FTD) is an umbrella term for a diverse group of uncommon disorders that primarily affect the frontal and temporal lobes of the brain, which are the areas generally associated with personality, behaviour and

language (MFMER, 2011). These dementias include primary progressive aphasia, Pick's disease and progressive supranuclear palsy (USAA, 2012). In frontotemporal dementia, portions of these lobes atrophy and signs and symptoms vary, depending upon the portion of the brain affected, which can include changes in personality, social disinhibition, impulsivity, emotional indifference, or problems associated with the ability to use and understand language (MFMER, 2011). In some cases this type of dementia is misdiagnosed as a psychiatric problem or as Alzheimer's disease, but frontotemporal dementia tends to occur at a younger age (between 40 and 70 years) than Alzheimer's disease, and survival years are less than for Alzheimer's disease (USAA, 2012; FMER, 2011).

The heterogeneous nature of dementia has many implications for the workforce and service providers operating within aged care. At palliative stages disease types of dementia appear similar. However, at early and middle stages of dementia the individual differences of disease expression in combination with the variance across disease type creates numerous complexities for the caring role of employees. In addition, roles and duties, and the extent of support provided by carers are contingent upon the nature and rate of disease progression. Carers can therefore face sudden and unpredictable changes in their roles. Employees care for multiple people with different types of dementia at varying disease stages. Thus, employees operate within a sporadic work environment and are continually required to adjust. Knowing how to provide training and capacity building to the dementia care workforce is complicated by the multiplicity of the disease itself. Acknowledging the complexities of dementia and the varied skill set required by employees is vital for training and education.

In 2010, 35.6 million people were diagnosed with dementia worldwide, and estimates suggest that this number will nearly double every 20 years, to 65.7 million by 2030, and 115.4 million in 2050 (WHO & ADI, 2012). The total number of new cases of dementia each year worldwide is nearly 7.7 million, which equates to, one new case every four seconds (WHO & ADI, 2012). Low and middle income countries will have the highest proportion of dementia as they have the greatest potential for new cases due to expected ageing trends (WHO & ADI, 2012). In Europe, 5.4 million people in the European Union (EU) had dementia, with this population predicted to double in Western Europe and treble in Eastern Europe by 2040 (Ferri et al., 2005). In 2011, 256,500 Australians were estimated to have dementia with predictions of this reaching a total of 9810,000 by 2050 (AE, 2010). The largest percentage of growth is predicted for those above the age of 75 years (AE, 2010). If dementia rates remain stable, and no change occurs due to treatment or management of the disease, the number of older Australians with dementia is projected to increase by 150% (AIHW, 2007). It may be that developments in the treatment of AD lead to a reduction in the current trends in morbidity and mortality, however research that aims to understand how disease and injury affect the brain and develop therapeutic agents that inhibit the degeneration of nerve cells (Pountney et al., 2004) is at the early stages (Vickers, 2002). Therefore, until therapeutic methods of treatment are developed, the prevalence of dementia is likely to continue to increase and place additional burden on service providers in the community (AE, 2009; Wimo, Winblad, Auero-Torres & Von Strauss, 2003).

Economic costs of dementia

The global economic burdens of dementia have been estimated to be US \$604 billion in 2010, the equivalent of 1% of the world's gross domestic product, with approximately 70% of the costs occurring in Western Europe and the United States (Wimo & Prince, 2010). Wimo and Prince (2010) authored The Global Impact of Dementia report published by ADI. The method used to estimate the costs of dementia was a societal, prevalence-based gross cost of illness study with annual costs per person with dementia for each country applied to the estimated number affected in that country, and then aggregated up to the level of the WHO regions, and World Bank income groupings (Wimo & Prince, 2010). Three main areas of data were used measuring the prevalence of dementia. The resources used for direct medical, social and informal care, as well as the costs attached to the resources that are used across countries worldwide. Estimates are based on absence of background changes (such as the pace of economic development, incidence and prevalence of dementia and effective treatment or cure) in the last forecast of dementia prevalence in 2009, and found that by 2030 worldwide societal costs will have increased by 85% (Wimo & Prince, 2010).

Costs associated with informal care, provided by family members and unpaid carers, and formal social care such as community-based and residential care were found to contribute similar proportions (42%), whereas direct medical costs made a much lower contribution (16%). There are differences between informal, formal and direct care costs of dementia care per region for low, middle and high income countries costs. Informal care costs account for two thirds of all costs in low and middle income countries compared to approximately 40% in high income countries. Direct care costs in low income countries account for only one

tenth of expenditure, whereas in high income countries costs associated with direct care (such as direct medical care) account for nearly half of all costs (Wimo & Prince, 2010). Disparity between informal, formal and direct care costs in different regions may partly relate to the lower costs per individual in these countries, particularly for lower income countries.

Internationally, estimates have been made that determine the costs per individual with dementia per country. The highest care costs per individual were found for the United States (US \$60,090) and the lowest for China (US \$2,641; Wimo & Prince, 2010). Four regions, Australia, the European Union, Canada and the United Kingdom show similar costs per person with dementia ranging from US \$34,552 to \$30,804 (Wimo & Prince, 2010). An earlier report determined individual costs divided on the severity of the disease and found in the United Kingdom that costs ranged from £14,540 for somebody with mild dementia living in the community to £20,355 for moderately-severe dementia living in the community to £31,263 per year for those living in care homes (Knapp & Prince, 2007). The ranges in costs for dementia per person per region not only differ due to local economies and health systems, but also due to the nature and severity of the disease, as well as the locale of care. Treating people with dementia early in their disease trajectory in the community encounters the lowest costs, whereas costs associated with caring for people with advanced stages of dementia living in a residential facility are highest. The marked differences in costs are likely to attract policy makers and governmental bodies to systems of community care over and above residential care, as a way to manage the encumbered economic costs of dementia.

Dementia costs in the United Kingdom have been shown to be more than cancer and heart disease combined (£23 billion per year), however, research in dementia is severely underfunded, receiving much less support than cancer or heart disease research (Luengo-Fernandez, Leal, & Gray, 2010). A 30-fold increase is needed for dementia to achieve parity with cancer research, and 15-fold increase is required to reach parity of research into heart disease (Luengo-Fernandez et al., 2010). Alzheimer's Disease International (2010) recommend dementia be made a priority worldwide by local governments increasing their commitment to reduce the burdens associated with the disease through increased levels of funding for both research and systems of care. Further, co-ordination of international research is needed to make the best use of resources.

Care needs of people with dementia

The care needs of people with dementia are dependent upon several factors. The degenerative nature of dementia means that patients can have various levels of functioning at different stages of their illness, with their abilities more likely to be limited the closer they become to advanced stages (Moise, Schwarzingler, & Um, 2004). This has implications for the type of care people with dementia require. In the early and moderate stages, the person with dementia may be cared for in his or her home. The person with dementia may live as independently as she or he can with services including an array of "in-home" care from home maintenance to personal care, often defined by assistance with daily living activities such as showering and bathing. In comparison, advanced stages of the disease may lead the person with dementia to be cared for in a residential facility where high care needs can be met with the assistance of nursing staff and care assistants. The distinction between each stage is not precise, and individual

patients will move along the continuum at different rates. Figure 1 (Moise et al., 2004) shows the continuum of care for people with dementia, including the initial stage of assessment and diagnosis.

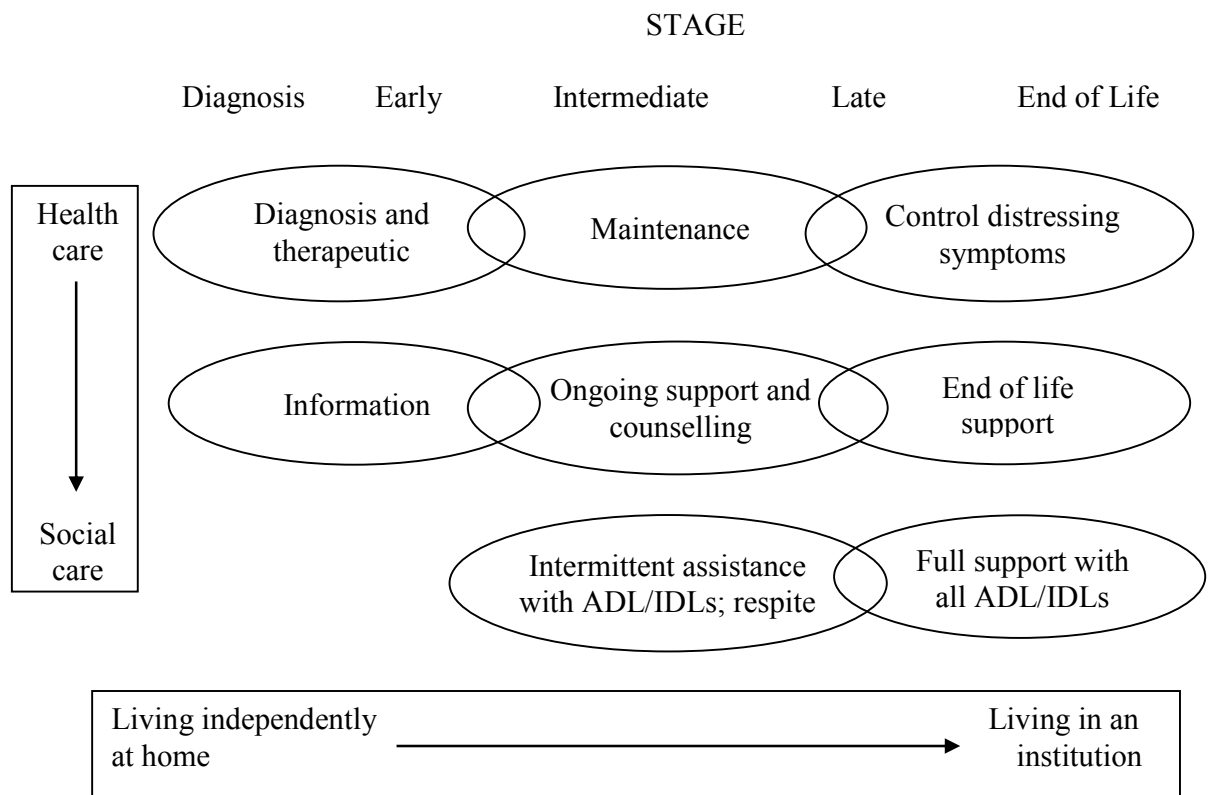


Figure 1. Care continuum for dementia patients by Moise et al. (2004).

The ellipses in Figure 1 are purposely displayed as overlapping as there is no clear distinction between each phase of care across the continuum (Moise et al., 2004). The ellipse labelled “Diagnosis and therapeutic” relates to the initial phase when patients are dealing with diagnostic tests and assessments and behavioural therapies. The “Maintenance” ellipse instead describes a focus on the maintenance of functions, such as drug treatment to minimise common comorbidities associated with dementia (e.g., depressive symptoms). The “Control distressing symptoms” ellipse displays the need for people with dementia to have treatment to minimise and cope with distressing symptoms, such as aggressive behaviours. Further along the care continuum is “Information” intended for support and caregiver education. The responsibility of providing information to patients and carers often falls between health and social care. Some countries show clear distinctions between the organisational management of health and social care, whereas others do not, hence Moise et al.’s (2004) decision to incorporate the use of a continuum to describe the care needs of people with dementia. The “Ongoing support and counselling” ellipse refers to a shift in focus of support and counselling for the caregiver, although specific needs for support and reassurance are still appropriate for the person with dementia at this stage. The “End of life support and counselling” ellipse relates to a need for palliative care and assistance with issues associated with end of life such as funeral preparations and grief and loss counselling.

The two ellipses at the bottom end of the continuum closest to social care are “Intermittent assistance with Activities of Daily Living (ADLs) / Instrumental Activities of Daily Living (IADLs); respite care” and “Full support with all ADLs / IADLs”. These two ellipses represent the support people with dementia need

related to their activities of daily living which include personal care such as bathing, dressing, toileting, and eating. At the early and intermediate stages of disease, people with dementia are likely to be able to undertake some (or part) of these activities independently, whereas during late stages of the disease the care recipient can be fully dependent on others in order to undertake such activities. Respite care aimed at providing a break from caring responsibilities for the caregiver is also included at the social care end of the continuum. The needs of people with dementia vary over the time course of the disease and what may occur for one individual at a certain stage may not occur for another. Hence, individually tailored care plans are essential to uphold quality care and meet the needs of people with dementia.

The top five needs reported by people with dementia, their carers and staff of residential nursing homes based in different geographical areas in the United Kingdom included daytime activities, aids for eyesight/hearing, relief of psychological distress, company, and information (Orell et al., 2008). These findings were consistent with a systematic review that found the most common subjective needs for people with dementia were related to coping with losses, self-esteem and social contact (Van Der Roest et al., 2007). In addition, people with dementia can face more complex needs and certain target groups have been identified in the literature where patients may have a unique set of care needs. These include people from culturally and linguistically diverse backgrounds (CALD; AE, 2006); Aboriginal people (Kountouras et al., 2009; Smith et al., 2008) and people with early onset dementia (Van Vliet, De Vugt, Bakker, Koopmans, & Verhey, 2010). It also includes people with dementia who reside in rural and remote areas (Morgan et al., 2009). For example, a report focusing on

the number of people with dementia who do not speak English at home found that 12.4% of Australians with dementia, almost one in eight, do not speak English at home (AE, 2006). This proportion of the dementia population is also increasing (Aged & Community Services Australia, 2011), which has implications associated with the need for cultural sensitivity and language specific informational resources for people with dementia from culturally and linguistically diverse backgrounds.

Many health services consider dementia a disability, as the person diagnosed with the disease will lose function of behavioural aspects and personality traits that contribute towards his or her independence. A disability may be generally defined as a condition which may restrict an individuals' mental, sensory, or mobility functions to undertake or perform a task in the same way as a person who does not have a disability (Disability Works Australia; DWA, 2010). According to the Disability Discrimination Act (Commonwealth of Australia; CoA, 1992):

Disability, in relation to a person means: Total or partial loss of the person's bodily or mental functions... or a disorder... or disease that affects a person's thought processes, perception of reality, emotions or judgment or that results in disturbed behaviour... (p. 4).

Health professionals are often involved with the advocacy of people with dementia, and are frequently called upon to determine whether an older adult is at undue risk of exploitation and in particular, financial exploitation (Pinsker, McFarland, & Pachana, 2010), which can relate to the individuals' level of disability. In the dementia setting there can be situations where the patients' cognitive capacity to make certain judgments regarding his or her options for health treatment and financial decisions are assessed by health professionals

(Pachana, 2007). In some cases this can result in legal arrangements (e.g., power of attorney and enduring guardianship) by a family member to make decisions on behalf of the person with dementia. People with dementia have the right to not be discriminated against based on their functional limitations. Therefore, it is paramount that there are provisions in policy and service delivery that provide people with dementia with opportunities to maximise their potential for community participation, and bridge the gap of functional disability.

Existing theories of stigma posit that possessing a disability such as dementia can result in a perception of difference between the person and others in the community, and potentially predispose the person with dementia to stigmatisation and discrimination (Nolan, McCarron, McCallion, & Murphy-Lawless, 2006). Dementia related stigma can interfere with and affect a patient's needs. Stigma can act as an obstacle to the well-being and quality of life of individuals with dementia and their carers, as it may interfere with access to care, and how care is provided (Nolan et al., 2006). For example, stigma has been shown to influence delays in dementia recognition and diagnosis in primary care. This can occur as a result of the person with dementia, or family members and others concealing, minimising or ignoring early signs and symptoms (Myrra et al., 2005). Further, stigma of dementia has been found to increase the burden of the disease on carers (Werner, Mittelman, Goldstein, & Heinik, 2012). Therefore, accessing services may be more of a challenge for dementia carers in comparison to other types of carers, due to the stigma and lack of public awareness about the disease. Further, stigma has been found to extend to the professional setting where general practitioners often delay diagnosis of dementia (Kaduszkiewicz, Röntgen, Mossakowski, & van den Bussche, 2009; WHO & ADI, 2012).

In Australia, community perceptions of Alzheimer's disease and other dementias are influenced by stigma, with 44% of the general population believing that people with dementia are discriminated against or unfairly treated (Pfizer Health; PH, 2010). Carers reported that they had experienced social isolation after the person they cared for received a diagnosis of Alzheimer's disease or other dementia. A common experience was friends and relatives reduced or stopped their usual contact. Further, reports by the general population found that 22% of Australians reported they would feel uncomfortable spending time with someone who had dementia (PH, 2010). Not only do people with dementia experience a complex array of physical, cognitive and psychological symptoms associated with the progressive and disabling nature of their condition, they too endure the effects of lack of understanding within the community and subsequent stigma and discrimination. Therefore, the care needs of people with dementia are diverse and not only determined by the disease itself, but also by the response of others to their condition. The role of the caregiver is also affected by the person with dementia's needs, and the prevalence of stigma within the Australian community highlights the need for advocacy of the person with dementia and his or her caregiver.

The care needs of people with dementia are complex. Symptoms such as personality and behavioural changes can make providing care in ADLs challenging, as rejection of care behaviours are common in people with dementia (Ishii, Streim, & Saliba, 2012). In some cases, people with dementia can lose their ability to determine whether or not their behaviour is socially appropriate. This is due to the dysfunction in the frontal lobes of the brain where control over impulsivity and behavioural regulation occur (Mendez & Shapira, 2011). Neurological changes can result in behavioural changes that can include

sexualised behaviours and aggression (Cipriani, Vedovello, Nuti, & Di Fiorino, 2011). In addition, symptoms can include psychotic features, such as delusions (Onur & Yalinay, 2011). Further, cognitive decline and problems with executive function, memory retrieval and encoding of new memory has implications for caring for people with dementia. People with dementia can lack awareness of the disease and experience confusion, and distress (Mendez & Shapira, 2011). For example, monitoring the person with dementia's general health is complicated by the disease symptoms such as lack of self-awareness and loss of comprehension. There is a growing body of empirical work supporting the effectiveness of non-pharmacological interventions for improving or maintaining important skills such as short-term memory, verbal communication, or self-care (Buchanan, Christenson, Houlihan, & Ostrom, 2011). Caregivers, however, are often not provided with additional tools to encourage such interventions, and further to manage the behavioural or emotional aspects of the disease beyond recommendations to attend support groups, or are given general advice such as "keep the patient active" (Buchanan et al., 2011, p.10).

Without guidance and recommendations on how to provide care for a complex disorder, negative effects can occur. Sometimes the care tasks of supporting someone with dementia can lead to significant stress and frustration resulting in abuse of care recipients (Cooper, Blanchard, Selwood, Walker, & Livingston, 2010). The abuse can include mistreatment from both informal and professional carers and can fall generally within six types. These include verbal and psychological abuse, physical abuse, sexual abuse, economical abuse and discriminatory abuse (Selwood & Cooper, 2009). A review of abuse of people with dementia found a discrepancy between patient disclosures about abuse and

official staff reports. While prevalence rates indicate that approximately 6-25% of older adults experienced abuse within the last month, official reports of abuse to authorities represented a much lower incidence (1%; Selwood & Cooper, 2009). Further, people with dementia are thought to be particularly vulnerable to abusive situations (Selwood & Cooper, 2009). This vulnerability relates to the fact that the symptoms of dementia align with several general risk factors that are associated with abuse and exploitation in later life. These include cognitive impairment, extreme dependence, frailty, social isolation, and severe physical illness (Pinsker et al., 2010). Risk factors of abuse in the care relationship have also been identified. Potentially harmful caregiver behaviour has been found to be more likely in spouse care giving situations and when care recipients have greater needs for care, and caregivers have more physical symptoms, and are at risk for clinical depression (Beach et al., 2005). One way to manage the potential risks for both the person with dementia and carer is to improve carers' capacity to care using education and guidance. Interventions have been found to reduce caregiver symptoms of depression (Mittelman, Roth, Coon, & Haley, 2004) and thus may also prevent abuse. Training and building awareness in such interventions are likely to be important for both informal and formal caregivers to be able to best meet the complex care needs of people with dementia.

Informal carers' needs

For family members and friends, the caring role can be both rewarding and also impact greatly on personal well-being (Ribeiro & Paú, 2008). Further, the disease may impact upon the emotional and psychological adjustment of the spouses and family members of people with dementia, who experience burden as part of their caring role (Campbell et al., 2008; Selwood, Johnston, Katona,

Lyketsos, & Livingston, 2007). People with dementia become dependent on others, both physically and mentally as the disease progresses (Georges et al., 2008). The burden on the caregiver also increases as the patient's functioning deteriorates (Georges et al., 2008). Greater functional impairment and problem behaviours in the care recipient also predict higher carer burden and depression in carers (Molyneux, McCarthy, McEniff, Cryan, & Conroy, 2008). Thus, carers' practical and emotional support needs are multiple and dynamic. Carers' needs interact with the person with dementia and are affected by their state of health and behaviours.

Similar to the needs of the person with dementia, caregivers can face more complex needs with certain groups identified as having additional set of care needs (i.e., CALD groups and early onset dementia). Whether or not there is a difference of impact on caregivers of early versus late onset dementia is unclear, but there is consensus that early onset dementia caregivers experience high levels of psychological distress and specific problems related to their phase in life (Van Vilet et al., 2010). In particular, caregivers experience high levels of burden and suffer from depressive symptoms and they experience psychosocial problems, such as relationship difficulties, family conflict, employment and financial issues, and negative experiences regarding the diagnostic process (Van Vilet et al., 2010). Health and social support systems and the professionals delivering services to people with dementia and their caregivers need be aware how to support cases where complex needs exists.

The exact number of informal dementia carers in Australia is unclear, as there is no single data source for estimate calculations. Instead, reports have adopted the use of several sources to determine dementia prevalence (i.e.,

Australian Institute of Health and Welfare, 2007). Two main reports (Access Economics; AE, 2009; Australian Health Ministers' Conference; AHMC, 2006) both use data from the Australian Bureau of Statistics Survey of Disability, Ageing and Carers (SDAC). In addition, the Dementia in Australia report collated by the Australian Institute of Health and Welfare (AIHW, 2007) use another eight sources, two of which include the National Hospital Morbidity Database and the Aged Care Assessment Program. Despite the differences in data sources, estimates show that there are between 12,200 – 23,200 people who provide care to someone with dementia in Australia (AE, 2009; AIHW, 2007). Further, it is estimated that 65% of carers are co-resident, as they provide assistance and live in the same accommodation as the person with dementia (AIHW, 2007). A current need exists for research and governing bodies in Australia to develop better recording and reporting processes to ensure an accurate picture can be provided for dementia care service delivery nationally.

In the United States, in 2008, the economic value of the care provided by family and other unpaid caregivers of people with Alzheimer's disease and other dementias was \$94 billion (USAA, 2009). In Australia, estimates show it would cost \$30.56 billion to replace all informal dementia carers based on 2005 data from Access Economics (AE, 2005). The economical contribution of informal carers highlights the importance of sustaining caregivers' capacity to care. Further, good carer self-management and coping predicts longer time to patients' institutionalisation, and fewer hospitalisations (Spijker et al., 2008). Therefore, caregivers play an important role facilitating patients' well-being trajectories and diversion of expenditure otherwise required in dementia care.

A review of 1,181 dementia carers in five European countries (France, Germany, Poland, Scotland, and Spain) found half of the caring population cared for more than 10 hours each day (Georges et al., 2008). Another dementia specific informal care survey of 1,000 households found a similar scene exists in Australia, as the average time spent caring was 16 hours per week, however, 18% of carers spent 40 hours or more per week looking after a family member or friend with dementia (ABS, 2008b; AE, 2009). These findings have further implications for carers managing not only the psychological effects of assisting a person with dementia, but also the practical and financial responsibilities, as many find they are unable to continue employment to sustain income, leading to greater likelihood of experiencing difficulties paying bills and borrowing money (ABS, 2008b; USAA, 2009).

Almost 10 million Americans provided unpaid care for a person with Alzheimer's disease or other dementia and in 2008, they provided a total of 8.5 billion hours of unpaid care (USAA, 2009). In 2005, 2.6 million Australian dementia carers (16% of the population) provided informal unpaid care amounting to 1.2 billion hours (ABS, 2008b; AE, 2005). More carers in Australia are women, which is similar to statistics on dementia carers in the United States, where 60% of carer workers are women (ABS, 2008b; StollzNow, 2007; USAA, 2009). In Australia, women carers were also likely to take on a caring role earlier than men (ABS, 2008b). In the United States, the greater proportion of carers of people with dementia are aged between 35-64 years (USAA, 2009). Similar to the United States, the average age of the Australian carer is 48 years, however this relates to general carers including caring for someone with a disability or chronic illness, and not dementia only (ABS, 2008b). Due to the slow degeneration of

Alzheimer's disease and other dementias, carers most commonly spend up to three to four years in their role assisting a friend or family member (StollzNow, 2007; USAA, 2009).

In Australia 52% of carers received one or more community care services, while 44% received none (StollzNow, 2007). Four out of five carers in Europe reported wanting more information on help and support services and half wanted more information on drug treatments (Georges et al., 2008). Informal carers play a main role in caring for people with dementia and often take on responsibilities of managing the person with dementia's activities of daily living, their general health and access to primary care and support services. Further, informal carers are a valuable resource in the community. However, for caregivers to remain effective in their role, further access to tailored support services may be a common unmet need.

Dementia Care Services

Worldwide there are different dimensions of care for people with dementia and at the foundation care responsibilities fall to the family. There are no effective health care treatments for a dementia cure, which is why the social care aspect plays an important role in treating the disease, with family members an integral part of this process (Moise et al., 2004). For developing countries, providing health care for the entire population is complicated by limited resources and overspending on high-technology facilities in larger cities, often leaving little funding for primary care, particularly in rural and urban areas (Tulchinsky & Varavikova, 2009). Despite the progress many low income countries have made in implementing fundamental services such as immunization and prenatal care, millions of preventable deaths occur annually because of lack of basic primary

care programs (Tulchinsky & Varavikova, 2009). Subsequently, low income countries may struggle to place dementia care as a high health priority.

Dementia care covers a wide range of services that vary in setting and type of care provided to patients. The variation occurs due to the wide range of people involved in care delivery including the family, public and privately operated services that can include health care, social care, housing income support, and legal advice (Moise et al., 2004). There is a high degree of complexity in care services due to the multiple providers, setting and caregivers, where the co-ordination of such services becomes paramount for quality care. One example of this includes the Australian situation where the employer ownership profile (of community care organisations) is driven by the third party financing model, whereby the Federal Government seeks tender for social care service delivery that are often filled by independent organisations who quote lowest service delivery costs. In this arrangement, the government provides financial backing but is not directly involved in the administration of the arrangements surrounding delivery, nor is it involved in shaping the workforce arrangements that will support delivery (Community Services & Health Industry Skills Council; CSHISC, 2008). These outsourcing decisions have blurred, confused and fragmented the employer profile for the sector (CSHISC, 2008) and have created problems for workforce regulations.

Over the last several decades there has been a move away from institutionalised care to providing care based in the community, often referred to by the aged care sector as ageing in place (AE, 2009). Ageing in place is a concept used to describe the living arrangements of individuals who grow old while remaining in their personal homes (Harris, 1988). The desire to age in place has

been identified by Horner and Boldy (2008) as a critical element of quality of life and significant for social connection, while also placing some burden on carers, family and organisations. A recent literature review on ageing in place found access to quality support services was the most commonly cited factor affecting the length of time older adult residents remained in their homes, and costly and intensive interventions were not necessarily needed in all cases (Locke, Lam, Henry, & Brow, 2011). Indeed, assistance with simple housekeeping and lifting of heavy objects were two of the most widely reported unmet service needs. Changes to the physical environment that incorporate accessibility features (such as lever door handles, ramps, wider doorways to accommodate wheelchairs, nonslip floor surfaces, and bathroom aids) were found to be necessary for successful ageing in place (Locke et al., 2011). Despite identifying some common unmet needs for older adults living at home, the review by Lock et al. (2011) did not focus on the specific service needs of people with dementia to age in place. These additional services are likely to relate to the aforementioned set of needs for people with dementia and their caregivers (highlighted in the previous section), and may include access to informational and educational resources about the disease and other health care treatments such as medication and symptom management.

The ageing in place trend is motivated by higher quality of life for older adults including people with dementia, and further driven by the high economic costs associated with providing institutionalised care (AE, 2009). Despite the logical argument behind ageing in place, little evidence has shown improvements in quality of life for those residents who remain in their home. However, there is evidence indicating that psychosocial decline occurs in older adults who move into residential care to secure appropriate care needs. In particular, depression

plays a major role in the early nursing home placement of dementia patients living in the community (Dorenlot, Harboun, Bige, Henrard, & Ankri, 2005).

Considering the findings from the review by Locke et al. (2011), access to quality support services for people with dementia remaining in their home may include referral for treatment of depression to reduce early nursing home admission.

Often caring for people with dementia falls within general aged care services, which have over time adapted or in some cases developed specialised units and care teams to meet the unique set of needs posed by Alzheimer's and other dementias. However, there has been some confusion within the public health sector about which services are responsible for the diagnosis, treatment and support of people with dementia. For example, over the last 30 years the United Kingdom have struggled to have dementia specific public policy, which Gilliard (2008) believed was influenced by the division in responsibility for services to people with dementia, such as general aged care and mental health care. Globally, there are similarities in the type of care services for people with dementia, one of these being the delivery of programs at the local level. In Australia, there is a three tiered systems of aged care that includes nursing homes (high-level residential care), hostels (low-level residential care) and support programs for people living in the community (Henderson & Caplan, 2008). Although this three tier system exists, the delivery of services in social welfare and aged care has been reported to be dominated by private sector contractors, with not-for-profit and for-profit organisations leading community services (CSHISC, 2008). These services are often funded on a short-term basis, commonly over a three year period, which influences long-term planning and care consistency. Despite administration and

funding, generally, formal care for people with dementia can be divided into two main areas that include community and residential care.

Community care

There is a wide array of services provided for people with dementia under the overarching arm of community care. Usually the services are provided in the care recipient's home or within the community setting (AE, 2010) and can sometimes be referred to as home care (Alzheimer Europe; AEurope, 2009). These services commonly aim to uphold the quality of life of people with dementia, their carers and family, and provide support with social and health problems (Ploeg et al., 2009). The services are available in most countries and can focus on providing assistance with the person with dementia's home (such as cleaning, shopping, laundry, transport and delivered meals) and or their personal care (such as washing, dressing, eating, incontinence care and medication; AEurope, 2009). In Australia, community care has been defined in terms that it is the provision of personal care services and assistance to a person not in residential care (Henderson & Caplan, 2008). Generally speaking, the aim of community care is to ensure that the person with dementia can age in place and services often follow mission statements that uphold a client's independence.

Community care can be provided with or without assistance from informal caregivers and can include a combination of both personal care and household maintenance and support. In some cases, older adults with dementia may have short stays in temporary care facilities which can include a daytime or overnight stay at a care centre, which is still considered part of the sphere of community care, as institutional care is usually considered permanent residence (Moise et al., 2004). Table 1 displays an array of community care services available across

different countries, including caregiver support in the form of education, financial assistance and respite. The nine countries displayed in Table 1 are part of the Organisation for Economic Co-operation and Development (OECD; Moise et al., 2004).

Table 1

Care Support in the Community Setting Across Nine Countries (adapted from Moise et al., 2004)

COUNTRY	TYPE OF CARE			
	Education	Financial	Respite	Community
Australia	Carer Education and Workforce Training Project (short-term) Dementia Education and Support Program Dementia Hotline	Carer payment (for full-time carer) Carer Allowance (for heavy caring responsibilities) Financial assistance with home modifications	Residential Respite (short-term care in RAC facilities) Carer Respite Centre (at day care centre or at home)	ADL & nursing help Home and Community Care Program: Community Aged Care & Extended Aged Care at Home (dementia specific)
Canada (Ontario)	Online dementia education for medical professionals Dementia-specific family caregiver education at AD organisations	Income-restricted carer tax credit Sales tax exemption for respite care (15%)	In-home respite Day adult programs at community centre Long-term care (LTC) - respite beds for short stays	ADL & nursing help Community Care Access Centres

COUNTRY	TYPE OF CARE			
	Education	Financial	Respite	Community
France	Dementia-specific education programs at AD organisations	Personalised allowance for autonomy	Respite hospitalisation program Group living	ADL help & nursing services part funded by retirement schemes and social welfare ^a
Germany	No dementia specific program, but participation in educational programs is free of charge. Dementia-specific program through AD chapters.	Long term care insurance (LTC Supp. Act) for dementia Contribution to pension insurance	Day centres	Dementia-specific home care (through LTC Supp. Act)
Japan	Yes dementia-specific information for health professionals and the public through the Medical Centre for Dementia estb. 2008 ^b	LTC insurance	Group living	ADL, nursing and rehabilitation service provision depending on patient need (covered through LTC insurance)

COUNTRY	TYPE OF CARE			
	Education	Financial	Respite	Community
Spain	Dementia-specific education programs at AD organisations	Tax relief	Expert centres (run by medical services) Assisted living	Home care (available in 20% of country ³) as systematic ADL and nursing help services are being developed.
Sweden	No dementia specific program, but small support groups.	Carer payment (as high as formal home helper payments for working age carers)	1-2 weeks short-term respite care Respite care at home (regular shift model home/care centre) Group living	ADL help Dementia-specific community care. Eligibility varies among municipalities
The United Kingdom	Dementia training for staff, online resource database for informal and formal carers and helpline provided by AD organisations	Carer's allowance	Day centres Respite admissions to hospitals, nursing homes or residential homes	ADL & nursing help Dementia-specific community care. Care from registered nurse is provided free by NHS.

COUNTRY	TYPE OF CARE			
	Education	Financial	Respite	Community
The United States	No dementia specific program, but private organisations provide information and education.	Cash payments or vouchers for services and supplies Tax credit (30%)	Available in most States. Service delivery and funding varies.	ADL help Medicaid-eligible people can get services. For home health care, doctor's certification is needed.

Note. ^a Alzheimer Europe (2009); ^b Awata (2010)

Of the nine OCED countries, six have dementia specific education programs provided by the government. In countries where there is no government dementia education program this service is provided by national Alzheimer's disease societies (i.e., Deutsche Alzheimer Geschaft, Alzheimer Society of Canada and Association France Alzheimer). All community care programs provide assistance with ADLs, with some including nursing assistance and are dementia specific. Some countries provide specific health care legislation detailing citizen rights to receive care. Most informal carers receive some form of financial assistance with some countries providing tax incentives for accessing care. The ways in which community care differs across each OECD country is determined by the infrastructure of that country, both in terms of physical buildings and health systems. Despite the range of service delivery, most countries have access to care support in the form of educational information, financial assistance, respite and community care, but the effectiveness of these services to meet both current and future demand remains relatively untested and unknown.

In Australia, the Federal Government funds a number of formal care options for people living in the community. These include services within Home and Community Care (HACC) that can include Community Aged Care Packages (CACP) such as Extended Aged Care at Home (EACH) and a similar dementia focused package called EACH-D (AE, 2010). An Aged Care Assessment Team (ACAT) is also funded to conduct assessments that inform patients' care needs and determine eligibility to receive services (AE, 2010). The support services that operate within these programs are varied and can include transport, home maintenance, personal care, domestic assistance and food services. In addition, eligible patients and carers can also access social support, counselling, nursing,

allied health care and rehabilitation services within community care. Table 2 shows examples of assistance provided under the umbrella of community support programs in Australia. These services provide assistance to older adults and people with disabilities, which can include people with dementia.

Table 2

Examples of Assistance provided Under the Umbrella of Community Care by Henderson and Caplan (2008)

Type of Support	Example
Domestic assistance	House cleaning, washing and ironing, shopping, transport (e.g., to appointments of bank), general (e.g., paying bills, helping with telephone calls).
Personal care	Bathing, dressing, personal grooming (e.g., shaving), eating.
Meals	Delivering prepared meals, occasionally some cooking
Social support	Friendly visiting services for companionship, assisting with paperwork (e.g., bills and banking).
Respite	Centre-based day care, in home respite, outings / excursions.
Other	Falls management, dementia support services (e.g., behavioural management and advice), equipment, home modification and maintenance, accommodation issues support, medication support, carer support, allied health services (e.g., physiotherapy, occupational therapy), community nursing (e.g., wound dressings), continence management, financial services and interpreters.

In Australia, there are a large number of small independent service organisations providing HACC services that follow national services standards which have transitioned over time from a focus on compliance to continual quality improvement (Henderson & Caplan, 2008). Most of these services make their own assessments of clients accessing the service, which can lead to problems with care co-ordination and fragmented care (Henderson & Caplan, 2008). Within HACC funding initiatives, special needs have been identified for people from CALD populations accessing community care. In particular, lower rates of CALD populations have been found to access HACC services (e.g., using fewer types of support services and less hours of care), in comparison to English as a first language population (Thomas, Woodhouse, Rees-Mackenzie, & Jeon, 2007). The independent organisations may not be providing adequate information about the services in a culturally appropriate way within the community. Future capacity building interventions may therefore need to focus on delivering services to CALD populations.

Australian estimates have been made by Access Economics on behalf of Alzheimer's Australia about the number of people with dementia expected to access HACC services, indicated that approximately 966,710 people in total will have accessed HACC services throughout 2009-10, with 19% expected to have dementia (AE, 2010). Of the Australian States, Tasmania and South Australia are expected to have the higher proportion (5.6%) of HACC clients (AE, 2010). The number of community care packages in Australia in 2009 averaged 23.1 package per 1,000 people aged 70 years and over (AE, 2010). In some instances, these services involve the care recipient paying a fee to receive support. This fee is in part subsidised by the national public health co-ordination system *Medicare*.

Dementia specific care packages (EACH-D) can also be accessed by patients and are individually planned and co-ordinated care plans tailored to help older Australians manage the psychological and behavioural symptoms associated with the disease (Department of Health and Ageing; DoHA, 2008). Recent increases to fund more care packages has been welcome by the Australian community (Young, 2011). However, more than an increase in the number of care packages is needed to ensure best use of resources. Policy makers need to explore ways to build the capacity of the already existing service providers prior to demand doubling.

In the United Kingdom, nearly two-thirds of people with dementia live in the community and a third in care homes (Bourn et al., 2007). A similar situation exists in Australia, where in 2008, approximately 60.3% of people with dementia (137,182) lived in the community (AE, 2009). This is lower than internationally, but slightly higher than earlier Australian estimates, which may reflect a trend of an increase in the number of people with dementia living in the community over time. The concurrent complex care needs of older people living in the community and a trend towards an increased demand on higher standards of care will leave community care services with an agenda to improve quality of care (Henderson & Caplan, 2008). This is likely to lead to an increased need for further training and education both at an organisational and worker level. How to best meet these demands in the community is currently under debate with research evidence starting to grasp such inquiry (Elliott, Scott, Stirling, Martin & Robinson, 2012). While there is a growth in the prevalence of people with dementia living in the community, accessing community care services, there is also an increase in the number of people with dementia that live in residential care.

Residential care

Residential care can range from larger scale nursing homes where older adults reside in supported accommodation and generally receive high-level care, to smaller specialised group homes or units. Residential care is an option for older adults when community care is not desirable or feasible and access to informal care is limited (AE, 2009). Internationally, there are differences in the way residential facilities are organised such as the physical environment and the organisational systems in which they operate, however, they all share a common goal to provide support and care to older people who can no longer live independently due to their deteriorating health.

In residential care homes most care is provided by professional staff, however, in some settings volunteer staff may also assist in care provision. Depending on the type of centre, care can be delivered with low or high intensity and staff can range from care assistants to medical professionals. Few reliable estimates of the proportion of people with dementia living in these facilities, as opposed to their own homes in the community exist, with estimates for the United Kingdom ranging between 35 to 50%, and for Canada 45 to 50% (Wimo & Prince, 2010). Many people with dementia reside in nursing homes, particularly towards the end stages of the disease where high care needs meet advanced symptoms. Table 3 shows long-term care options across nine OECD countries (Moise et al., 2004).

Table 3

Long Term Care Support across Nine Countries (adapted from Moise et al., 2004)

Country	Long-term care (LTC)
Australia	People with a high level of disability and care needs (assessed by ACATs) may be admitted (40% of people with dementia are in aged care homes). 60% of residents have dementia ^a
Canada (Ontario)	Community Care Access Centres determine eligibility for & authorise admission to LTC facilities.
France	Chosen as last resort. Seldom a deliberate choice for the elderly
Germany	Short-term, part-time (day or night) and full-time institutional care is available 60% of residents have dementia
Japan	People aged 65+ needing nursing care, who are insured by LTC insurance may be admitted
Spain	Admission depends on existence of carer among the person's relatives Varying levels of medical care provided
Sweden	Those elderly who are in very extensive need of care and attention may be admitted Some special dementia care units exist within nursing home facilities
The United Kingdom	Means tested admission to LTC facilities Nursing care is available for free to everyone in care home who needs it
The United States	More than half of the Medicaid funding is spent on institutional care 50% of residents have dementia

In Australia, information is available about the health conditions of residents in aged care facilities, however this is limited. Access Economics (2009b) estimates are based on data from the ABS (2004) SDAC. In 2010, there were approximately 82,815 permanent residents in residential care with dementia (approximately 49% of all residents), with 69,047 classified as high care and 13,768 classified as low care dementia residents (AE, 2009b). Caution is made regarding these figures due to the developments in dementia diagnosis since 2003, when the SDAC was conducted. However, a report produced by AIHW (2010) stated that approximately 60% of residents in aged care facilities have a diagnosis of dementia. This shows an increase of approximately 11% of people living with dementia in residential care facilities over six years.

In Australia, residential care provides accommodation, living services (e.g., cleaning, laundry, and meals) and assistance with personal tasks (dressing, eating, and bathing), as well as access to allied health and nursing care when needed (AE, 2009). There are two types of care in a residential care facility in Australia, low and high-level care. Low-level care includes accommodation services such as meals, laundry, room cleaning as well as help with personal care, and some nursing support. High-level care is usually provided to people who need assistance to complete most daily living activities. It includes much the same services as low-level care, with medication needs managed by nursing staff, and further support with personal care and mobility. Prior to moving into a residential facility, often the care recipient will undergo an assessment of their needs to determine which level of care she or he requires.

Despite the divisions between high and low care, there is a trend for nursing homes and residential care facilities to more commonly deal with

palliative care, with reports of residents median length of stay equating five months in a nursing home before death (Kelly et al., 2010). In the United States, 25% of all deaths occur in nursing homes with this proportion rising, as by 2020, an estimated 40% of Americans will die in a nursing home (Weitzen, Teno, Fennell, & Mor, 2003). In Australian residential care for 2008-2009, 38% of permanent residents were in residential care for less than one year with 27% of these for less than six months and 88% of these residents died in care (AIHW, 2010). A review of the total number of residents in aged care homes in Australia over a decade (1999 to 2009) has shown a 20% increase in the number of permanent residents, with a 36% increase of residents aged 85 years or over (AIHW, 2010). These reports match international trends of increases in the older-old and subsequent use of residential care. The focus of dementia as a terminal illness and the need for palliative care will affect service delivery in residential care homes and may contribute to the institutionalisation of death.

In Australia, residential aged care services take up the majority of all government expenditure on aged care services (66%) and in 2008–09, expenditure on aged care services was \$10.1 billion (Steering Committee for the Review of Government Service Provision; SCRGSP, 2010). The number of aged care places in Australia is determined by ratio planning, and in 2009 there were 86.9 operational places per 1,000 people over the age of 70 years, with a small proportion of these places (2%) used for respite care options (DoHA, 2009). The location of these places is determined by need, such as prevalence of disability and the number of alternative services in the region. As of 30 June 2009, there were 2,783 residential aged care facilities with 175,225 operational places compared with 2,830 residential aged care facilities, providing 172,657 places at 30 June

2008 (AIHW, 2010). Aged care costs are focused on residential care with increases in places occurring. Whether or not the resources are available to match the predicted need is a challenge countries including Australia will face in the next several decades.

Some forms of residential care take the physical structure of “homelike” units. Such homelike units are being offered for people with dementia, where the emphasis of care is placed on “normal daily life”. A literature review comparing homelike care environments internationally showed some units were based on larger residential care facilities, whereas others were based in the community. Most homelike units catered for eight to fifteen residents and followed care models that focused on social care aspects with emphasis on including family and keeping residents connected with social networks (Verbeek, Van Rossum, Zwakhalen, Kempen, & Hamers, 2009). The physical environment often mimicked a home environment with spaces for a kitchen, laundry, living rooms and gardens. Caution was made regarding the development and implementation of homelike units where there appeared to be a tension between the focus on everyday life and meeting the medical needs of people with dementia (Verbeek et al., 2009). In particular, Verbeek et al. (2009) raised concerns about the potential loss of professionalism that can occur when too much emphasis is given to normalisation of living for older people with dementia. Cost comparisons were difficult to perform. However, most authors included in the review implied the smaller care environments were more economical than larger nursing home environments, despite some not taking into account extra support services required and potential hospital stays. Little evidence is available on the cost of smaller residential care environments despite some reports of benefits for people with

dementia. Therefore, more research is required to determine whether or not smaller dementia specific homelike units are a potential avenue for effective resource use and care path for patients.

Conclusion

The ageing population is pervasive and has implications for many facets of life, one of which is risk associated with dementia. Dementia is a term used to encapsulate an array of diseases with similar features, mainly with a neurodegenerative focus that impact upon individual cognition and behaviour. Expedient growth of dementia across the world will lead to higher costs for health care and a greater need for innovation in service delivery considering the current fiscal environment. Due to the diversity of disease expression and individual differences, the needs of people with dementia and their caregivers are varied and change over time. In addition, some proportions of patients and carers experience difficulties of access to support associated with language barriers and remote or regional living. Needs differ over the time course of the disease and what may occur for one individual at a certain stage may not occur for another. Therefore, the range of services available to patients and carers is required to be as varied as patient and carer needs, if quality standards of care are to be met. This will have implications for organisations required to deliver flexible and adaptive support services. Access to community-based quality support services commonly affects older adult residents' likelihood of remaining in their own home, with symptoms of depression a major contributor to early nursing home placements. Support services need to include a wider scope than simply providing practical assistance with activities of daily living and environmental alterations to reduce disability associated with mobility and physical impairments. The psychological

health of older adults also needs to be considered, providing access to appropriate therapeutic intervention.

Informal carers not only play a facilitating role in the management of a patient's well-being but also offer considerable economic contribution to dementia care. Maintaining informal carers' capacity to care can be viewed as an asset for governing bodies. Many informal carers take on the caring role with little knowledge of the disease and the caring role. Further, carers can face sudden and unpredictable changes in their roles based on the multiplicity of the dementia experience. While many informal carers receive support in their care role some do not, with most asking for more information on available services. Improvements in access to available services is needed for people with dementia and their caregivers, a difficult task for administrators considering staff recruitment and retention issues in the workforce.

In most high income countries, people with dementia have access to a range of support services that include disease specific education and information, financial assistance, respite and community care. However, this may not be the case for people in low income countries. In both high and low income countries, there has been a shift away from institutionalised care towards ageing in place with most people diagnosed with dementia living in the community. Contributing to this shift are several factors such as the relatively cheaper costs of providing support to older adults living in the community compared to those in nursing home care in high income countries. Another factor is lack of care facilities in low income countries, as well as a cultural change away from institutionalisation that fosters residents desire to remain living in their homes. However, the shift away from institutionalised care has excluded people in the end stages of life such as

people with advanced dementia, as residential care facilities and nursing home are more commonly dealing with palliative care needs. These changes have implications for specialised training as there will be an increased need for dementia education specific to the work setting and expansion in the community sphere. Ageing in place and the concurrent complex care needs of older people living in the community, and a trend towards an increased demand on higher standards of care make for a clear agenda for community care services to improve quality of care. Future capacity building interventions may need to focus on improvements in delivering services to particular populations considered to have a unique set of needs, such as people from CALD backgrounds or in regional and rural areas. Thus, the factors that enable the workforce to deliver quality services will be examined in the following chapter. This will include a description of the characteristics of dementia care workforces in Australia and internationally. Issues of engagement in training relevant for workforce development will also be presented. Further, problems of recruitment and retention, as well as staff well-being and satisfaction will be highlighted in Chapter Two. Examining the aforementioned areas will help determine how these factors may contribute to, or hinder capacity building for the future.

Chapter 2

The Characteristics of the Dementia Care Workforce

“The key to this new era of dementia care must be informing, inspiring, educating and training the diverse workforce that delivers care and services to the people with dementia and their carers”.

A comment made by Neil Hunt, Chief Executive Alzheimer’s Society, United Kingdom (2008, p.11).

Dementia Care Workforce

Internationally the workforce providing care to people with dementia is varied. Occupational distribution is often difficult to discuss on an international level, considering the nature of various classification and health care systems across nations. Overlapping responsibilities and roles, multiple levels of work titles and differing qualification systems such as licensed workers or active professionals contributes to this quandary (IOM, 2008). One perspective is that the “dementia workforce is itself a complex concept and could include the vast majority of staff working in physical health care, mental health care, residential and nursing care and social care” (Benbow, Tsaroucha, Ashley, Morgan & Kingston, 2011, p.195).

According to the WHO (2006), health care workers are all people engaged in actions whose primary intent is to enhance health. Based on this definition, the WHO (2006) estimated there is a total of 59.2 million full-time paid health workers worldwide. Despite the differences in access to health workers across various nations, the WHO (2006) predicted that the demand for health services will escalate across all countries of high or low wealth. In addition, large numbers of health care workers will be retiring at the same time the demand for health care is increasing (McGinnis et al., 2005). The dementia care labour force is no exception, and estimates of exponential growth to cater for demands are expected within the next several decades. This workforce also faces problems of multi-disciplinary dementia competency in rural and remote areas worldwide (Morgan, Innes, & Kosteniuk, 2011). In response to the findings of the 2006 report by the WHO, the Global Health Workforce Alliance (GHWA) was formed as an entity entirely devoted to helping resolve the crisis in human resources for health. The

GHWA has been in operation for six years and has produced several strategic documents including innovative examples of ways that countries, in different resource settings, are solving problems, and has also recently launched a five year initiative to strengthen medical education in Africa (WHO, 2012). While the GHWA's approach is commendable, its overall focus is on general health, however, may still inform capacity building for dementia care at an international level.

One of the main occupational groups providing care and assistance to people with dementia is formal or professional carers. Formal carers have many vocational titles and are known as direct care workers, support workers, care workers, and aged care assistants, and work primarily in settings important in the care of older adults such as nursing homes, assisted living facilities and in-home care settings (IOM, 2008). In some instances the classification of formal carers can also include other workers providing services to people with dementia. These occupations range from nurse assistants, trained or registered nurses, geriatric specialist psychiatrists, medical practitioners, oral health professionals, social workers, psychologists and other allied health workers, such as diversional therapists. The roles of workers supporting people with dementia are varied and there are many different levels of training associated with each role.

While focusing on occupational grouping, client target groups and service sector groups that operate within aged and dementia care can provide a framework to review differences in training and professional development, this approach has limitations. There are challenges in the definitions relating to the diversity in clients and services. These include an ambiguity in sector boundaries and operation in the spaces "in-between" residential care, employment, legal, and

allied health services (CSHISC, 2008). The shift in how occupational groups operate within sectors over the past several decades has meant that multi-disciplinary models of care are often preferred and have implications for training and professional development needs due to changes in traditional daily work duties. Further, the workforce includes those who are not involved in care tasks such as administration and non-clinical or non-care staff, who provide valuable support in the every-day delivery of services. Often evaluations of the health and community or social care workforce surveys omit such information regarding this proportion of staff. Acknowledging these organisational factors are necessary when considering workforce demographics and information about client engagement with sector and services, particularly when determining key priorities for skill development.

The combined community services and health workforce form Australia's largest employer group accounting for 11.4% of all workers, with 1.3 million workers, the fastest growing industry group (CSHISC, 2011). This workforce includes a range of workers to deliver programs to older adults living in the community. Some of these include community support workers, enrolled nurses, home care workers, home maintenance workers and in-home respite caregivers. In the 12 months from December 2009 to December 2010 more than 100,000 workers joined the community services and health sector, which translated to an annual growth of 8.6% (CSHISC, 2011). Regardless of this growth, the sector is still under-staffed to meet the expected demands on services, which will be further hampered by the current workforce reaching retiring age. In this sector the current ratio of workers to retirees is 5:1, however, by 2050 it is expected to be 3:1 (CSHISC, 2011). Managers and administrative executives will need to be creative

and focus on innovation if they are to solve the workforce supply and demand issues in community care.

Workforce participation data for professional carers of people with dementia rely on surveys of the health and community and or social care services and the aged care sector in general, such as audits of nursing homes and aged care facilities. Little information is available specific to those workers involved in care of people with dementia, especially for allied health professionals and physicians. More data is available on direct care workers, who participate in some forms of clinical aged or disability care, as well as activities of personal care such as assistance with bathing, dressing housekeeping and food preparation (IOM, 2008). In the United States, in 2006 there were 2.3 million direct care workers, primarily working in settings important in the care of older adults such as nursing homes, assisted living facilities and home-care settings (IOM, 2008; US Bureau of Labour Statistics; USBLS, 2008). Direct care workers in the United States were either nurse aides or nursing assistants, home health aides and personal and home care aides (Harmuth & Dyson, 2005). Much the same as in the United States, Australia provides care to older adults in both residential aged care facilities and in the community setting where people with dementia receive support services while remaining in their own home (Martin & King, 2008). According to the National Institute of Labour Studies' report on the residential and community based care workforce in Australia, in 2007, 175,000 people were employed in residential aged care facilities and approximately 87,500 were employed in community based outlets providing aged care under Commonwealth supported programs (Martin & King, 2008). Reviewing workforce participation by aggregate means there is a

risk of missing distinctive patterns that might be exclusive to the individual industry, which may be true of dementia care workers (CSHISC, 2008).

Estimating the population and characteristics of the dementia care workforce in Australia is complicated by the organisational structure of the sector (i.e., employer ownership profile). Despite these complexities, an evaluation by Access Economics (2009) of the number of people with dementia living in residential aged care facilities and the hours of care provided by employees (taking into account leave and full-time equivalent work status) estimated there were 76,000 to 80,000 dementia care staff in Australian residential aged care facilities in 2008. Following similar data evaluation processes, there were 84,000 formal care staff caring for people with dementia in the community setting, including services such as *Meals on Wheels*, linen and cleaning support and transportation assistance (AE, 2008b). While reports show the combined community services and health workforce in Australia is expanding, it is difficult to determine particular patterns of growth for the dementia care workforce, which forms a part of the overall community services and health industry.

Internationally, demand is growing for caregivers, especially for community based settings and these type of occupations are one of the occupational groups with the largest projected job growth this decade (Booth, Roy, Jenkins, Clayton, & Sutcliffe, 2005; US Department of Labour, 2010; Paraprofessional Healthcare Institute, 2011). There are several similarities in the characteristics of these workforces internationally. On average the American care worker is more likely to be female (89%), between the age of 25-55 years, unmarried (including widowed, divorced or separated) and with no university education (Montgomery, Holley, Deichert, & Kosloski, 2005; Smith &

Baughman, 2007; Yamada, 2002). Further, ethnicity of care workers in the United States is likely to be white-non-Hispanic with 30% African American and 16% Hispanic, Latino. Most direct care workers in the United States are approximately 42 years of age and have high school diploma or less education, and 46% have family poverty status and rely on public benefits (Figueriredo, 2011). In the Australian aged care setting, a typical worker as described by Martin and King (2008) is:

... Female, Australian born, aged about 50, in good health, has at least 12 years of schooling and some relevant post school qualification and works 16-34 hours per week. She is likely to be a Personal Carer or Community Care Worker, working a regular daytime shift (p. 3)

On average the Australian care worker is mostly employed on a part-time basis, with only 8% employed on a permanent basis (Booth et al., 2005). In addition, large numbers of health care workers will be retiring at the same time the demand for health care is increasing (McGinnis et al., 2005) and in Australia, nurses working in aged care are still paid at a lower rate than nurses working in the acute sector (Doyle, 2009). The training and education backgrounds, remuneration rates, as well as intrinsic person variables of aged care workers may be factors to consider in attracting and preparing workers for the ageing population, and projected increase in proportion of older adults with dementia.

In the United States, work population projections in health care suggest that an additional 3.5 million health care providers are needed by 2030 to maintain the current ratio of health care workers to the population (IOM, 2008). In Australia, the demand for formal care is also higher than the supply, as the proportion of people with dementia needing assistance will outweigh the amount

of carers available in the future (AE, 2009). Overall, the current workforce in Australia of paid and unpaid carers of people with dementia is estimated to need to increase by 76% within two decades to meet the anticipated rapid rise in demand for services (AE, 2009). Therefore, in the future, the shifting health workforce will require new skill sets to manage new models of care, as well as disciplinary collaboration and continuity of care (IOM, 2008; USBLS, 2008; WHO, 2006). Further, training, education and research are all areas where considerable development may be needed, particularly in light of retention issues and job dissatisfaction faced by many residential aged care facilities and in the aged care and the nursing sector in general (AE, 2009; Aiken, Clarke, Sloane, Sochalski, & Silber, 2002; Hayes et al., 2006; Spence Laschinger, Leiter, Day, & Gilin, 2009). Recruitment and attraction of workers to the dementia care sector are other issues raised by the literature.

Specific information pertaining to the dementia care workforce can be found in the United Kingdom health setting. A recent study set in the United Kingdom focused on the dementia care workforce and found differences between the general social care workforce and the dementia care workforce (Hussein & Manthorpe, 2011). This study included those employees identified as working in social care services that explicitly provide services for older people with dementia compared to workers in other settings. The dementia care workforce was more likely to be female, to work part-time, to be employed by agencies and to be less qualified, with many employees working for medium-sized care businesses and in people's own homes (Hussein & Manthorpe, 2011). Further, dementia care workers were significantly more likely to not be working towards any qualifications (7%), and 9% of dementia care workers held no qualifications. The

proportion of non-British workers was significantly higher among the dementia care workforce than the rest of the social care workforce, which was illustrative of a larger trend across social care (Hussein & Manthorpe, 2011). Professionals and managers or supervisory staff were less commonly found in the dementia care workforce in comparison to other services, which was reflective of the large proportion of employees working in-home/community care with substantial autonomy and little supervisory or managerial contact (Hussein & Manthorpe, 2011). Such small numbers of supervisory staff in community dementia care may have implications for the standard of care people with dementia receive.

The National Framework for Action on Dementia was developed as part of an agreement between health ministers in Australia as a way to respond to the dementia epidemic (AHMC, 2006). Workforce and training was one of five key areas identified for priority attention. Since its development, the NFAD has delivered a review of the outcomes. Three areas of workforce and training were under review. These included firstly a focus on access to education, training and information. Secondly a focus on the incorporation of dementia into national and state workforce issues, and thirdly the informing of the health and aged care system and community preparedness (Horner & Doyle, 2011). While some positive outcomes were reported, such as the formalisation and prioritisation of discussion of education and training at Dementia Working Groups, most outcomes highlighted the need for further developments in training. Dementia specific training, with particular improvements in diagnosis and assessment were shown to be a need in order to achieve a more seamless and co-ordinated care model. Funding constraints and competing priorities in the health and aged care system were seen as barriers that affected the capacity to inform community preparedness

(Horner & Doyle, 2011). Both internationally, and in Australia initiatives are developing with regard to training and education for the professional dementia workforce. Some commendable training interventions have shown promising effects, while others are currently being trailed following ideal methods such as the randomised control design (Beer et al., 2011; Beer et al., 2010; Chenoweth et al., 2011; Downs et al., 2006; Jeon et al., 2012; Kuske et al., 2009). Developments in this area will help to inform policies and practices at the coal face, which is an area in need of urgent reform.

Qualifications and Training

The care needs of people with dementia are managed by a combination of a limited number of professional staff, including nurses, general practitioners and old age psychiatrists and a much greater number of carer workers. Martin and King (2008) acknowledged that the average aged care worker in Australia has at least 12 years of formal training and some type of post-school qualification. This is likely to be a Certificate III in Aged Care or Home and Community Care. At most residential care facilities in Australia the Certificate III in Aged Care is the major qualification used to train personal care workers (Booth et al., 2005). The majority of workers in dementia care have low qualifications and enhancing workers' skills and knowledge is bound to form part of any reform. How best to address the workforce development agenda is still being debated internationally.

One way to review the level of qualifications in community and residential care worldwide is to focus on occupations that require a certain level of training and education. The required qualifications in aged care are typically fairly low around the globe, although there are some exceptions. Germany has employees with qualifications as a major part of the long-term care sector. In general, the

required qualifications are considered lower in home and community care than in institutional settings (Colombo, Llena-Nozal, Mercier, & Tjadens, 2011).

Internationally, the number of nurses in long-term care range between 16% (Japan) and 85% (Hungary), however, it is common for most countries to have fewer than half of workers providing long-term care as nurses (Colombo et al., 2011). Qualifications are considered higher for those occupations that require tertiary education and training, such as gerontology, and nurses, but the numbers of such professionals in aged and long-term care are outweighed by the larger proportion of low qualified workers.

In Australia, most organisations delivering HACC services require care staff to have at least Certificate III training, however there is no statutory requirement for this standard, and in some cases care workers need no training, and may instead undergo some form of service orientation and training through the workplace. Not only is there no legal requirement from the Australian Federal Government of a minimum standard of training in dementia to be undertaken before commencing this type of work, there is also a lack of a professional body to offer safeguards for clients and consumers (Doyle, 2009). In some cases care workers may undergo basic training while starting at an organisation, with the ability to transfer their learning from a course to their job tasks (Booth et al., 2005). In 2007, the UK General Social Care Council made recommendations that residential and domiciliary social care workers must gain a relevant qualification, however Bourn et al. (2007) noted that this did not necessarily include training in dementia.

The situation in the United States differs slightly from that of Australia and the United Kingdom, as there are qualification and training requirements for

particular parts of the care workforce. The US Government requires training only for nursing assistants and home health aides who work in *Medicare* and *Medicaid* certified nursing homes and home health agencies, although States and individual employers may require training and or certification for other types of direct care workers (Paraprofessional Healthcare Institute; PHI, 2011). While recommendations exist at a governing level for training and qualification requirements, a lack of legislation and regulation can be found internationally regarding the dementia care workforce. The only exception to this problem of regulation can be found in relation to allied health professionals, where at an occupational level accrediting bodies are ensuring that education relating to older adults and dementia form part of the essential curriculum. This is evident for health professionals such as physicians, nurses, psychologists and social workers, who have had attended tertiary institutions to gain an adequate grounding in dementia in their basic training before registration, and there are variable incentives or requirements for continuing professional education in dementia (Doyle, 2009). Despite some regulation for tertiary trained health professionals, an unregulated bulk of the dementia care workforce still exists, which is likely to be problematic when transforming worker capacity to improve standards of care.

There has been an increase in the proportion of personal care workers with Certificate III in Aged Care in Australia, from 55% in 2003 to 65% in 2007 (Martin & King, 2008). A close review of the main form of qualification for care workers in Australia (Certificate III in Aged Care) shows that a total of 14 topics related to aged care must be completed (see Table 4). The Certificate III is part of the Community Services Training Package (CHC08; CoA, 2010) which details core and elective units care workers cover. Adherence to the training package lies

with the registered training provider, with recent suggestions for a review and update of content and accompanying resources relating to dementia (Doyle et al., 2009).

A registered training organisation (Inspire Education; IEP, 2012) advertises the Certificate III in Aged Care and states on the organisation's website that students will complete "80-240 hours workplace-based experience in a registered Aged Care facility to solidify... practical experience and skills in working with aged persons" (para. 8). While training aims to provide workers with information about caring for older adults, its focus is task specific and does not encompass an educational approach, whereby perspectives are broadened and employees can discover there can be multiple ways to approach the same situation or problem (Downs, Capstick, Baldwin, Surr & Bruce, 2009). This is one issue that policy makers and subsequent organisations delivering care must overcome if they are to create sustainable changes to knowledge and skill of the dementia workforce.

Table 4

Fourteen Topics Covered in the Certificate III in Aged Care (CHC08)

UNIT TYPE	
Core	Elective
<ul style="list-style-type: none"> • Ways to support older people to maintain their independence • Work effectively with older people and in the community sector • Provide support to people living with dementia and meet personal care needs, participate in the implementation of individualised plans • Support individual health and emotional well-being • Follow safety procedures for direct care work • Deliver care services using a palliative approach • Recognise healthy body systems in a health care context 	<ul style="list-style-type: none"> • Culturally aware and respectful practice • Client support • Medication • Organisational support • Supervision and training • Community care • Working with people with disabilities • Working with people with mental health issues or oral health

While on a practical level providing basic training in working with older people and dementia does to a certain degree enhance workers' abilities in preparation for higher demands, it is unlikely to diminish the overarching concerns of access to quality dementia care. It has been established that there are a range of effective ways to care and support people with dementia throughout the disease trajectory, from diagnosis to death (Andrews, McInerney, & Robinson, 2009; Bartels et al., 2003; Conn et al., 2006; Mittelman, Broadaty, Wallen, & Burns, 2008). However, these have not yet become an integral part of service delivery and practice (Downs et al., 2009). Higher Education in dementia studies is seen as a key priority to fulfil the role of building specialist knowledge and skills in dementia care, while providing elements neglected by skills-based workplace training, namely, the development of critical thinking, reflection and action (Downs et al., 2009). Further, there is a need for professionals to have greater understanding about evidence-based practice, and how these findings can be implemented into practice.

Tertiary courses in psychology, social work or other allied health professions require education in working with older adults and dementia. In comparison to these professionally focused courses, there are very little tertiary courses solely dedicated to dementia studies. Only three universities in Australia offer courses in dementia. These include the University of Wollongong, Edith Cowan University, and most recently the University of Tasmania. In the United Kingdom there are similar diploma, graduate or post graduate courses, such as those offered by Bradford University, which follow an intensive format (Downs et al., 2009). Innovation and creativity in dementia care service delivery are fundamental to meeting high future demands, particularly in light of the low cost

funding model, workforce shortages, and problems with recruitment and retention. Higher Education is one way to prepare future generations to access their analytical thinking to be able to implement practical and organisational processes that are derived from the rapidly developing literature on dementia care. Perhaps the best approach to improving the adequacy of dementia care is to ensure that at both ends of the training and education spectrum, programs are occurring where evaluation is prioritised. This may be reflected in the allocation of funding by governing bodies. Education and training outcomes need to be sustainable and practical, and benefit not only workers but also people with dementia and their family members.

Workforce engagement in training

Similar to other data collection in the area of dementia care, information on the number of dementia care workers attending skills-based workplace training is limited. In many countries this relates to the organisational structure of service delivery. In Australia, dementia care falls within aged care services under the general health and community care sector, of which some data is available on attendance at training. In Australia in 2005, the average number of hours spent on training by health and community care workers equalled 22.7 hours for permanent workers and 15.8 hours for casual workers. However, 28.9% of permanent and 43.8% of casual workers did not complete any training courses (CSHISC, 2008). Some employees expressed a desire to attend training but were unable to attend for varying reasons. The most commonly reported reasons by health and community services employees was “too much work”, “no time” and “financial reasons”. Other reasons included “lack of employer support”, “personal or family reasons” and “course related reasons” (p. 46). In addition, 69.2% of workers did

not have a desire to do more training. Table 5 shows the percentage of workers who completed either one or several courses (up to four) in 2005, and indicates whether the course was organised by the employer or an external provider (CSHISC, 2008). However, the training information collected from the Australian community services and health sector is not dementia specific. Despite this, problems of attendance related to poor time resources, further hampered by lack of desire or motivation for professional development, which may also be barriers to improving the capacity of the dementia care workforce (Booth et al., 2005). Service providers may need to consider organisational factors that allow in-house delivery of training, as this may be easily accessible and appealing for care workers.

Table 5

*Australian Health and Community Service Workers Patterns of Training Course**Activity in 2005 adapted from CSHISC (2008)*

Details of training undertaken	Employment status (%)	
	Permanent	Casual
Completed 1 course	21.5	20.2
Completed 2 courses	17.3	13.3
Completed 3 courses	11.2	9.6
Completed 4 courses	20.5	10.6
Training organised by employer	32.8	20.3
Training organised by external provider	20	27.3
Attended course/s organised by employer and external provider	18.4	8.6

Internationally, the responsibilities of training provision appear to be mixed between local Alzheimer associations and independent training organisations, with many countries providing training in dementia through these avenues for health professionals and care workers (AE, 2010; AEurope, 2009; USAA, 2011). Recently, national efforts have been undertaken in Australia to improve training provision in dementia. In particular, a focus on access to training formed part of a major National Dementia Initiative, with two main projects aiming to achieve improvements across the sector (residential and community care workforces; AHMC, 2006). The first project was a stock take of dementia curricula and training, undertaken to review the standard of the current content by inviting tertiary, vocational, industry and peak providers to participate in an online survey. Whereas the second project aimed to improve the skills of care workers and assess worker competency in dementia called the Dementia Care Essentials (DCE) program.

The study on dementia training content adopted an online survey to collect information and only recruited 35% of targeted training providers. Outcomes were described in a report by AITEC Corporate Education and Consultation on behalf of the Australian Department of Health and Ageing (2006). Of the organisations that responded, 72% indicated they provided relevant curricula, education and training and 90% of these provided data that contained information about 76 programs and 233 courses. Twenty-eight percent of the organisations that responded reported they did not provide any training. The review of training content was not only focused on dementia, but also included training for continence in the aged care sector. Thus, results were not dementia specific and the self-report nature of the survey may have created a positive bias, where

organisations were less likely to report not adhering to their training agenda. Employing objective measures or conducting an audit of programs and materials may be more relevant for future training stock take approaches. Further, equating effectiveness of the trainings to improve knowledge and skills may also be relevant for future research. Doyle et al. (2009) recommend that a more comprehensive sampling approach or a follow-up census is recommended to fully meet a national stock take of dementia curricula in Australia, to provide sufficient information to draw conclusions on training content of up to 233 courses. In addition, providing incentives (such as access to additional funding or resources) may be a way to improve recruitment rates of training providers in similar future projects.

The second part of the Dementia Care Essentials (DCE) project was established to improve access to dementia training in Australia. The training covered topics such as the nature of dementia, person-centred care and effective communication skills (including working in partnership with families). The provision of training for aged care workers in dementia care was according to the standards in a competency-based unit in the Community Services Training Package, called “Provide Care Support which is Responsive to the Specific Nature of Dementia” (CHCAC15A). This is a unit that forms part of the Certificate III and IV in Aged Care (Doyle et al., 2009). According to Fleming and FitzGerald (2009), the DCE training was well received and reported to be on track with a target of 17,000 aged care workers trained between 2006–2009. However, the preliminary evaluation by Fleming and FitzGerald (2009) is based on anecdotal reports from workers and managers, with empirical data on

improvements in workers' dementia knowledge and skills yet to be published in a peer-reviewed journal.

A brief overview of the findings of the DCE was described by Doyle et al. (2009) as part of an evaluation of the Dementia Training Initiative by the LAMA Consortium. While Doyle et al. (2009) reported "the outcomes demonstrated increased participant knowledge and skills, and the economic evaluation demonstrated an economic cost benefit" (p. 21), there was little detail provided on the data collection and analysis methods used to achieve this result. Despite this, the report offered valuable information on the engagement of the workforce in training. Difficulties were reported with targeting special needs groups such as people requiring assistance with English as a second language and those with an Indigenous background. In particular, a need was raised for liaising with networks that had long-term relationships with such groups (Doyle et al., 2009).

Training preferences of the dementia care workforce were highlighted by the preliminary findings of the DCE program, particularly relating to personal care workers. This group of workers were attracted to face-to-face training, with virtually no uptake of other options such as distance education and recognition of prior learning avenues (Fleming & FitzGerald, 2009). Similar findings occurred for a review of workplace training practices in residential care (Booth et al., 2005). In this setting, the majority of workers had lengthy experience in the same or similar roles in the industry, but still opted to complete the full Certificate III qualification and did not show interest to participate in the recognition of prior learning options. In the DCE program, reasons for providing alternative delivery of training (such as distance education) were to assist with less time off site and potential backfill or changing shift issues. In an attempt to overcome potential

barriers of access to training, the DCE program discovered that delivery that is not face-to-face is a barrier to attend training. Doyle et al. (2009), suggested that personal care workers may not be independent self-learners, which influenced their preferences for face-to-face training delivery. This training preference may also be linked to workers' up-take of recognition of prior learning avenues. Learning preferences of the care workforce need to be considered as part of any training plan or agenda, in order to make best use of resources and ensure the engagement of the workforce in training programs.

While the DCE training was provided free of charge to the worker to encourage participation, some organisations opted to pay for workers' time to attend, while other organisations encouraged workers to attend in their own time. Barriers were still evident with organisations needing to find replacement workers to deliver care in the absence of those workers attending training (Fleming & FitzGerald, 2009), a logistical concern that was the largest obstacle, more so than the financial costs of paying for workers to attend training. Not only should training content be consistent, reliable and up-to-date, it must also be easily accessible, as this workforce is time and resource poor. Several factors that are considered essential for skill growth in the health sector, include not only training, but also financing and models of funding (CSHISC, 2008). Other factors include organisational aspects such as the employer ownership profile and the structures of employment that are likely to impact on workforce enhancement (CSHISC, 2008). Job design and job perceptions are also important for attracting workers to the industry, as well as employee receptiveness to train and perceptions of client needs (CSHISC, 2008). Governments around the world will need to consider such factors if changes to workforces structure and capacity are to be sustainable.

One international example of a review of training content in dementia care, is that of Florida, in the United States (Hyer, Molinari, Kaplan & Jones 2010), where a comprehensive review of dementia knowledge and skills of the direct care workforce was undertaken. A total of 445 curricular were reviewed relating to dementia education and training over a period of four and a half years. Hyer et al. (2012) found problems of consistency of content across the training programs, mostly aimed at care workers employed in the residential setting. These problems included that not all training was person-centred, included clear objectives, time formats or a dyadic approach. Hyer et al. (2010) suggested a systematic approach to continue a credentialing process of dementia care workers. There is consensus that improvements are needed in consistency of training programs in dementia. This approach may provide a model for credentialing dementia training for the Australian setting. However, the Florida example has one clear advantage over the current Australian setting, as standards of training are legislated in Florida, but no such regulation currently exists in Australia.

Another approach to improve training and education in dementia has been to create a set of core competencies, based on a set of well-defined skills and knowledge. Eight core competencies have been proposed by Tsaroucha, Benbow, Kingston, and Le Mesurier (2011) to assist in the development of the dementia care workforce in the West Midlands region in the United Kingdom. The competencies included:

- i) Knowledge/awareness of dementia and dementia related issues;
- ii) Understanding the behaviours of individuals with dementia;

- iii) Enriching the life of individuals with dementia and their carers (e.g., support/help individuals with dementia engage in activities that are appropriate and meaningful to them);
- iv) Interaction with individuals with dementia;
- v) Interaction with carers/families;
- vi) Dementia worker personal development and self-care;
- vii) Person centred care; and,
- viii) Promoting best practice (p. 12).

These areas were derived from the findings of a literature review on competency frameworks and included interviews with dementia training providers, as well as key experts in university, non-government and acute care settings, and further consultation with patient and carers on workforce skills (Benbow et al., 2011; Tsaroucha et al., 2011). The eight competencies were published with several skills sets listed within each category that may be used as a tool for workers to self-assess their skills (to create learning plans), or organisations may adopt the framework to scope the skills of their workforce and use the findings to create an education strategy (Tsaroucha et al., 2011). Whether the eight competencies described here change practice are unknown. A competency based system for dementia care capacity building and workforce development for all professional groups is an admirable accomplishment. Thus, future evaluation is required to determine the efficacy of this framework, particularly regarding implementation for dementia care services. Further, human resource issues of recruitment and retention are also likely factors that will influence training and development approaches for the workforce.

Staff Recruitment and Retention

Health services research has focused extensively on topics related to attrition and staff turnover. Aged care, especially the dementia care labour sector is no exception to these investigations. There is a need for an aged care workforce strategy to recruit and retain workers with dementia knowledge and experience. A systematic literature review found the main reason for quitting the dementia care labour market was lack of job satisfaction, largely relating to negative worker appraisals of the quality of care provision (Vernooij-Dassen et al., 2009). Workers commonly reported feeling dissatisfied with the quality of care they were able to provide. Worker dissatisfaction may play a role to inhibit capacity building considering the negative effects of staff turnover.

High turnover has been linked to poor working conditions and contributes to a negative image of aged care. Not only is the attractiveness of the sector affected, so too are costs, as in the United States, turnover costs were calculated to be at least US \$2500 per vacancy (Colombo et al., 2011). International trends indicate working conditions and benefits for nurses in long-term aged care settings are generally poorer than in acute care (Colombo et al., 2011). Some countries that are members of the Convention on the Organisation for Economic Co-operation and Development (OECD) struggle to match the growing demand for aged care workers with the available supply, which is worsened by high turnover and low retention rates. Colombo et al. (2011) stated “workers to fill caregiving jobs can be found, as long as policy makers and employers take steps to improve the dismal image of caregiving as being low-paid, hard, and low-skilled” (p. 3). Not only are there negative effects for retention of nurses, lack of adequate numbers to deliver care have poor consequences for the quality of care available for consumers.

Negative attitudes toward aged care and dementia care are shared by general health professionals and caring for older people is not perceived as a popular career choice (Bowers, 2008). One way to improve the image of the aged care sector is to improve workers abilities and develop an image of a skilled workforce that is connected to professionalism. Several countries have taken this approach with successful outcomes. An example of this is in Holland and Germany where retention rates are higher than in the United States and the United Kingdom (Colombo et al., 2011). Dutch and German long-term care workers reported satisfaction with their conditions and responsibilities. In Germany, job redesign of nurses roles took place (e.g., responsibilities and daily tasks) to create elderly care nurses, with a positive impact on attractiveness of the sector for nurses (Colombo et al., 2011). One concern about “professionalising” a sector such as aged dementia care, relates to the change in entry to the workforce, from being relatively easy and flexible to more rigid, due to the potential to increase barriers associated with training requirements and regulatory systems. This change may be a concern as many workers chose to participate in the long-term care sector for its flexibility. Enhancing workers’ abilities, while maintaining a sense of flexibility in job roles is important to consider for future workforce participation.

If retention efforts are to be improved, understanding why care workers leave their roles will assist intervention aims and targets. In Northern Ireland, the main reasons given by home care workers for dissatisfaction and considering leaving were, irregular and antisocial hours, lack of management support and workload pressures, whereas commitment to caring seemed to be the reason why pay did not feature more highly for those who did not leave (Fleming & Taylor, 2007). Similar results were found for American direct care workers, where

commitment to caring was found to be the highest motivating factor for workers to participate in the sector, above and beyond pay conditions (Howes et al., 2008). Another study set in the United States found there were several factors linked to turnover in the direct care workforce (Mittal, Rosen, & Leana, 2009). Workers who were likely to leave the care industry stated concerns with a lack of respect, inadequate management and work or family conflicts. Difficulty of the work was also considered a reason to leave the job. Whereas factors associated with retention included being “called” to service and having a focus on patient advocacy. Other factors associated with staying at work in the long-term included a desire for personal relationships with residents, and that work was viewed as a “haven from home problems”. Flexibility in the nature of the work was also identified to contribute to retention of care workers. In both Northern Ireland and the United States, workers remained in their jobs from a sense of duty, attachment to their clients and through commitment to providing care, whereas those workers leaving the sector were sick of poor management support and high work demands. Improving access to managerial support and offering organisational support are imperative for retention efforts in the long term care sector. Workers, who operate in an environment of ever increasing responsibilities and risk in association with the complex health and social care needs of their clients, are calling out for practical and professional workplace support.

Preparing the workforce for increases in chronic disease may be hampered by retention problems, high staff turnover, and worker dissatisfaction, as currently these organisational factors are dramatically affecting aged care service providers (Hayes et al., 2006; Vernooij-Dassen et al., 2009; Willis-Shattuck et al., 2008). In particular, recruitment motivations for the health setting in developing countries

relate to access to good quality resources. These include financial rewards and career development opportunities such as continuing education (Willis-Shattuck et al., 2008). While factors relating to job conditions may motivate some workers to participate in the health care sector (particularly those in developing countries), stress and leadership issues have been found to be major contributors of dissatisfaction and intention to leave the workplace for nurses (Hayes et al., 2006). Keeping workers content in their job roles by providing adequate resources are likely to attract employees to the health care sector, while maintaining strong leadership and opportunities for workers to manage their stress are likely to keep workers satisfied. Research that tests recruitment interventions with such target outcomes may provide answers for policy makers who are looking to integrate effective recruitment strategies into long-term care reforms.

Despite the turnover and recruitment issues faced by the long-term care industry worldwide, Colombo et al. (2011) suggested that finding an adequate supply of long-term care workers is a manageable goal. One way to reach this goal is to extend the recruitment pools of workers and increase the retention of already recruited workers, while also finding ways to improve pay and conditions, as well as worker productivity (Colombo et al., 2011). Improving remuneration will dispense the notion that dementia care work requires less skill than other general or acute health positions, which Bowers (2008) suggested is reinforced by the relatively lower remuneration in dementia care than other areas of general health. A lack of strategy and evidence in how to make better use of workers and existing recruitment pools will worsen the current turnover and recruitment problems. While much evidence exists for effective dementia care strategies, less evidence for effective recruitment strategies in the dementia care employment sector is

available. Organisational theories offer some explanation of turnover and burnout in other occupational settings (e.g., hospitality and human resources; Chew & Chan, 2008; Cho, Johanson, & Guchait, 2009), and may further understanding about these factors in the health care and dementia setting. Experts in the area of dementia believe that increases in pay levels and qualifications of care assistants working with people with dementia are on the future agenda (Comas-Herrera et al., 2011) and will lead to improvements in current workforce problems. However, without adequately addressing related issues of worker staff well-being and job satisfaction, recruitment and retention efforts may prove difficult to overcome.

Staff Well-Being and Satisfaction

Job satisfaction has well-established links with high job demands and stress, and a meta-analysis of 31 studies of nurses found job satisfaction was most strongly correlated with job stress (Zangaro & Soeken, 2007). Job stress is considered a major factor for work-related injuries, workplace turnovers, absenteeism, and workers compensation claims at an international level (Richardson & Rothstein, 2008). The risks of developing a psychological disorder, such as a Major Depressive Episode, is higher for workers with high work demands, reduced autonomy (i.e., low decisional power and the lack of control over work), strain, overload and pressure (Bonde, 2008; Darr & Johns, 2008; Standsfeld & Candy, 2006). Care workers who feel unable to manage their work tasks or perhaps have difficulties managing particular behavioural symptoms of dementia are likely to experience some level of stress.

Job stress and burnout have implications for retaining workers in employment, as well as affecting their ability to participate in work roles. Several meta-analytic reviews conducted over five decades have established the

relationship between general health, psychological well-being, work stress and dissatisfaction (Bonde, 2008; Darr & Johns, 2008; Faragher, Cass, & Cooper, 2005; Kuoppala, Lamminpää, Liira, & Vainio, 2008; Standsfeld & Candy, 2006). Where much is known about distress in the workforce (see Table 6), especially for nurses, police and rescue workers, where high demands, low control and poor resources are linked to poor mental health outcomes (Bonde, 2008; Darr & Johns, 2008; Edwards & Burnard, 2003; Van Der Ploeg & Kleber, 2003), in comparison rigorous evidence about dementia care workers experience of distress is still growing. In particular, a systematic review of stress experienced by care staff of people with dementia found a lack of strong evidence across studies set in residential care (Pitfield, Shahriyarmolki, & Livingston, 2011). Two studies included in the review reported disparate prevalence rates of staff distress with Astrom, Nilsson, Norberg and Winblad (1990) finding 37% prevalence whereas Kuremyr, Kihlgren, Norberg, Astrom and Karlsson (1994) reported 5% of staff were “at risk” from burnout. In contrast, four studies reported low mean stress scores (Pitfield et al., 2011). Problems were found with the psychometric properties of the measures adopted by authors to assess distress in workers, which was acknowledged to contribute to a lack of good quality evidence. Generally dementia care workers experience some levels of job stress, however, the research evidence remains weak with only one systematic review in the area (Pitfield et al., 2011). This review was only focused on effects for workers in 24-hour care settings. Therefore it is yet to be tested, whether or not the same factors (e.g., high demands, low control and poor resources) are involved for poor mental health of dementia care workers than other occupations (i.e., police and rescue workers). Further research is warranted to investigate the effects of stress associated with the

dementia care role on retention and turnover, particularly with reference to psychometrically sound measures and intervention studies.

Participants & Design				Outcomes								
Study	N studies included [total screened]	Year limits	Occupational [ES]				Person [ES]					
			Perform- ance	Demand	Autonomy	Manage- ment	Work absence	Job satisfaction	Job strain	Mental health	Physical health	Social support
Standsfeld and Candy (2006)	11 [24,939]	1999- 2005			low decision & mental disorder [1.21]			effort-reward imbalance & mental disorders [1.84]	& mental disorder [1.82]	& job insecurity [1.33]		poor interpersonal relationships & mental disorder [1.32]
Faragher, Cass and Cooper (2005)	485 [ns]	1970-ns								& job satisfaction [0.31]	& job satisfaction [0.29]	

Participants & Design			Outcomes									
Study	N studies included [total screened]	Year limits	Occupational [ES]					Person [ES]				
			Perform- ance	Demand	Autonomy	Manage- ment	Work absence	Job satisfaction	Job strain	Mental health	Physical health	Social support
Systematic reviews primarily focused on general work settings												
Bonde (2008)	16 [749]	1966- 2007		high		low decision				high	depression symptoms	low
Systematic reviews primarily focused on health care work settings												
Michie and Williams (2003)	40 [ns]	1987- 1999	long hours & work overload		lack of control in decision making	unclear & work role & bullying	sick leave			work pressure	poor	sickness poor

Note. ES = effect size measured in Cohen's d; ns = not stated.

Stress is experienced by staff working with people with dementia and they face challenges in their daily job roles. While early career long-term care workers in the United States experienced stress more than later career workers (employed more than two years), they also experienced more hopeful and person-centred attitudes about people with dementia (Zimmerman et al., 2005). Length of experience in care work seems to effect the way workers' perceive their jobs, in particular early carer workers express overall higher levels of psychological arousal (i.e., presence of both distress and hope). It may be that caring for a long time reduces care workers' level of intense reaction to job situations and events and with more experience they may become less engaged and despondent. Intervention should consider length of employment when targeting certain psychological or training domains, with a potential to offer tailored programs for early versus later career workers.

The care setting may play a role to mediate stress for some dementia care workers. A Canadian rural study found differences between nursing aides who worked in specialised and non-specialised care units for people with dementia (Morgan, Stewart, D'Arcy, Forbes, & Lawson, 2005). Nursing aides in specialised care units reported lower job demands and strain, and less distress associated with exposure to disruptive behaviours than staff in non-specialised care units (Morgan et al., 2005). This may have implications for workers' stress in an environment which is not optimised for care delivery. A study from the Netherlands assessed the control and social support aspects of work in relation to job burnout for workers caring for people with dementia in group living environments. For workers in the group living environment, demands were low as was burnout, while control and support were high, also true for job satisfaction (Boekhorst, Willemse,

Depla, Eefsting, & Pot, 2008). Similar to the Canadian study, the work environment and small scale of the specialised homes for people with dementia appear to be connected to satisfied workers. Working in smaller teams with less number of care recipients may contribute to better staff cohesion and collegial or managerial support. The environmental design may also allow for care tasks to be more easily received by residents, who could feel more “at home” than “in care”.

Previous experience of caring appears to be related to job satisfaction for direct care workers caring for people with Alzheimer’s disease in the United States. Job satisfaction and care worker resilience were found to be lower in these workers who had prior training in gerontology and geriatrics, whereas those care workers who previously had a family caring role (e.g., Alzheimer’s disease or other dementia specific) showed higher levels of job satisfaction, but lower levels of career resilience than those without previous experience (Coogle, Parham, & Young, 2007). Past personal experience of caring may play an important role for the satisfaction of dementia care workers, and may therefore have implications for retention.

The most difficult aspects of working with people with dementia include coping with and managing disruptive behaviours (such as aggression and hostility) and the resistive, difficult and unpredictable nature of these behaviours were a challenge for Australian nurses working in residential care (Brodaty, Draper & Low, 2003). Overall most nurses were satisfied with their jobs, however, a quarter reported working with people with dementia did not provide any job satisfaction. More negative than positive views were held by nursing staff of people with dementia, in particular the five most prevalent perceptions of residents were that, they were anxious, had little control over their difficult behaviour, were

unpredictable, lonely and frightened and vulnerable (Brodaty et al., 2003). For dementia care workers who are based in residential care, job satisfaction is multifaceted and these workers can experience satisfaction in their job tasks and with the organisation while also experiencing negative perceptions of the clients they work with.

Occupational health psychology refers to the application of psychology to improving the quality of work life and to protection and promoting the safety, health and well-being of workers (Landy & Conte, 2007). Occupational health psychology interventions may be appropriate for workers who experience distress associated with high demands of working with people with dementia. There are two main approaches to interventions targeting improvements in worker well-being. One approach is to intervene by assisting workers to better manage their emotional responses to their work (i.e., individually targeted interventions) and another way is to intervene at an organisational level to create better work practices to alleviate stress associated with high demand and worker roles (organisationally targeted interventions). The type of stress management intervention adopted for different occupational settings has been found to have a moderating role on psychological well-being (Richardson & Rothstein, 2008). Larger effects were found for Cognitive Behavioural Therapy (CBT) interventions that target the individual, above other types of interventions such as relaxation, organisational, multimodal or alternative types such as diary writing, or classroom management training (Richardson & Rothstein, 2008). The majority of CBT interventions found to be efficacious in a meta-analysis were applied in the education and administrative settings for both teachers and office workers. Only eight of the 36 studies included intervention components that were focused on

organisational factors, such as strategies to increase workers' decision making or social support in the workplace (Richardson & Rothstein, 2008). While individually targeted interventions with a CBT focus appear to be the most efficacious for workers experiencing distress, less organisationally focussed interventions in comparison have been tested. Staff well-being and satisfaction appears to be one of the main predictors of commitment to the workplace and therefore warrants further investigation with regard to capacity building in the dementia care sector. Closely connected to staff well-being and satisfaction is workforce resilience, and how employees' cope with high job demands.

Workforce resilience

Resilience in the workforce has been applied to several occupational settings such as child protection services (Russ, Lonne, & Darlington, 2009), psychotherapists treating trauma patients (Hernández, Gangsei, & Engstrom, 2007) and nursing (Jackson, Firtko, & Edenborough, 2007). However, the concept of resilience is often explained following a developmental psychology approach applied mostly to children and adolescents, and less to cases of later life adjustment to loss and problems with cognition (Windle, 2011). Commonly the notion of dealing with adversity by bouncing back is central to the resilient experience in all work settings, where employees are exposed to high demands often leading to distress, or in some cases exposure to trauma. Therefore, dementia care workers who are observing the effects of a debilitating degenerative illness on their clients are likely to experience strong emotional responses such as grief and loss at work. In this way, dementia care workers may experience trauma vicariously. While exposure to these situations at work may in the short-term lead to negative adjustment, in the long-term workers may have positive adjustment

and have particular characteristics that enable them to be resilient in the face of adversity.

Relationships appear to be important for a resilient workforce. Jackson et al. (2007) presented a review of the literature on nursing resilience and reported the importance of several factors that included relationships such as “building positive and nurturing professional relationships... developing emotional insight... and becoming more reflective” (p. 1.). These factors, as well as maintaining positivity, achieving a life balance, and spirituality, were all suggested as strategies that had the potential to influence positive adjustment to adversity at work. Hartling (2008) argued that resilience can be strengthened through relationships that foster personal growth. This has implications for the workforce. An organisation that fosters supportive professional relationships that lead to personal growth may have a workforce capable of coping with high job demands.

Considering the strong links between job stress, dissatisfaction and employee resignation, strengthening workforce resilience may be a priority in dementia care, as a way to combat problems with retention. Further, Weeks, Wilkinson, and Davidson (2005) proposed that practice-based supportive frameworks that enhance relationships were essential to creating more positive models of care. Applying the principals of resilience to the dementia care workforce may be the innovative approach that will improve workforce retention. However, factors that contribute to workforce resilience in the dementia care setting remain unexplored, and will be a focus of the investigation.

Conclusion

Staff recruitment and retention problems currently impede the dementia care workforce, with particular concern for regional and rural areas where there

are issues of multi-disciplinary competency. Workers have low financial remuneration, low level qualifications and poor employment status, which contribute to an image that needs revising. While the social care workforce is one of the fastest growing occupational sectors worldwide, its expansion will be hampered by the current number of employees reaching retiring age. Most workers leave their jobs as they are dissatisfied with the level of quality care provision and experience distress and burnout. Ensuring control over work with access to effective resources in dementia care will assist with managing distress and burnout in the workforce. Finding ways to improve quality service provision and employment conditions are essential in a sustainable dementia care workforce.

Lack of regulation regarding entry qualifications, ongoing training and professional development stifle opportunities for service improvement. In aged care, dementia training is focused on task specific skill development and requires content and resources up-dating. A wider spectrum of education and training is also required that encompasses not only task specific, practical training, but also higher education that encourages analytical thinking and innovation with the ability to implement evidence-based practice in light of rapidly developing literature. A small number of countries agree more training is necessary and there are some suggestions of dementia care workers' training preferences. However, which training interventions produce the best effects in which setting remains relatively unknown despite the awareness of barriers of access and lack of motivation. Further, relationships appear to be an important aspect of workforce resilience in several occupational settings. Whether the same is true for the dementia care workforce is unknown, and investigating this area may be an innovative approach that will improve workforce retention. Determining the

relevant theoretical concepts for capacity building and training approaches may provide a sound basis from which to build interventions that produce strong effects. Thus, Chapter Three will explore multiple theoretical perspectives to highlight processes that may be essential for workforce development.

Chapter 3

Organisational, Clinical and Social Psychology Theoretical Frameworks

“Those who are in love with practice without knowledge are like the sailor who gets into a ship without rudder or compass and who never can be certain whether he is going. Practice must always be founded on sound theory”.

A quote from the journal of Leonardo da Vinci, Artist and Inventor (1452-1519, p.20).

A Tri-Theoretical Approach

Organisational theories have offered some explanation for worker productivity and turnover in various occupational settings, such as hospitality, human resources and general health care settings (Chew & Chan, 2008; Cho, Johanson, & Guchait, 2009; Darr & Johns, 2008). Whether these same theories can offer something new to the dementia care setting will be explored by the current thesis. Finding practical approaches with theoretical underpinnings to reduce turnover and improve recruitment in dementia care that are translatable, is likely to benefit communities worldwide. Organisational psychology theories that are relevant for service delivery in dementia care, namely the *job-demands and resources* model (Demerouti et al., 2001), *perceived organisational support* (Eisenberger et al., 1986) and *person-organisation fit* theory will be presented in this chapter.

The clinical psychological concepts that relate to individual worker functioning and skill development will also be introduced in this chapter and are relevant for capacity building. Concepts such as *self-efficacy* (Bandura & Adams, 1977), *role ambiguity* (Kahn et al., 1964), and *emotional labour* (Hochschild, 1983) will be described. The social psychological concept of *communion* (from Bakan's theory of agency and communion; 1966) will be presented to help account for responses of the dementia workforce to current and future work demands, considering the inherent social nature of the care role. Acknowledging that there are many theoretical perspectives that apply to the dementia care setting, these approaches have been selected for investigation because they offer unique explanations relevant to capacity building.

The theoretical approach underpinning the current thesis is based on the convergence of clinical, organisational and social psychological concepts that together offer a perspective accounting for processes essential to the success and sustainability of capacity research and innovation implementation. By taking this multi-discipline approach, it is envisaged that the combined strengths of each area will form an overarching and holistic approach that attempt to best utilise limited resources during the current fiscal environment. Following this approach may bring forth advancements in the field, paralleling the way psycho-oncology research has developed over the past ten years and is expected to continue to develop further in the translational arena (Cao, Depinho, Ernst, & Vousden, 2011).

Concepts that relate to organisational change and innovation spread will also be introduced to highlight contextual issues that can affect the implementation of changes in support services. While these concepts are not under close investigation in the current thesis, acknowledging the role they play in the translation of research to practice will add to the relevance of the findings. Organisational factors particular to dementia care such as work conditions, job tasks, leadership and supervision will be explored in later chapters.

Organisational Models

The application of psychological knowledge and principles to the work setting, was initially adopted in the first half of the 20th century during World War I, to examine personnel selection processes (Cooper & Locke, 2000). *Industrial Psychology* was the original term adopted in this field, mainly due to the practical application of applied psychologists working with factory workers and employees working in the industrial setting (O'Driscoll, Taylor, & Kalliath, 2003a). Distinctions are often made between industrial psychology and organisational

psychology, the main distinction relating to the origins of each field, with the latter developing after the former. The field of organisational psychology stemmed originally from social psychology, with theories and research focused on interpersonal behaviour, group dynamics, inter-group behaviour and macro-organisational behaviour (Cooper & Locke, 2000). Sometimes both terms are combined and research in the field of *Industrial and Organisational Psychology* (*I-O Psychology*) describes the behavioural aspects in the work context. Currently the field has expanded to include the study of emotional and motivational side of work, by investigating topics such as attitude, fairness, stress and leadership (Landy & Conte, 2007). Person variables such as job satisfaction and burnout are not the only area of interest in I-O psychology. Organisational structures and processes within the workplace such as organisational demands, learning culture and leadership, as well as role ambiguity and overload are some constructs that are well studied.

Organisational change theories provide specific approaches that offer explanation for organisations undergoing change, and generally focus on efficiency and social change. A distinction has been made between organisational change and transition. Organisational change is often a specific result of an intervention or alteration in business function and can be viewed as an outcome, whereas transition relates to the underlying processes of change (Bridges, 2003). Often the transitional process includes the psychological responses to a different way of organisational operation, such as feelings of loss in relation to the restructuring of roles and management. Organisational change management approaches tend to focus on strategies driven by the changes that need to occur with some reference given to the more personal transition activities needed to

ensure the success of a program. Three phases of transition in response to organisational change have been postulated by Bridges (2003). These firstly include an ending/losing/letting go of the current position, secondly, a disorienting neutral zone, and thirdly, a new beginning. Assisting employees to manage each phase and deal with emotional resistance may form part of the capacity building picture for dementia care, particularly if aged care reform brings about significant organisational changes.

Organisational change in the future of dementia care may include role changes such as expanding care tasks for direct care workers, changes to the system and operation of care. In Australia, the peak body on dementia, Alzheimer's Australia, has put forward discussion papers outlining an objective where the "consumer" has more control over how finances are allocated for care across various support programs, known as *consumer directed care* (Kodner, 2003). The idea behind the consumer focused changes is to set the overarching objective of giving people with dementia and their family carers the option of greater independence and choice in the services they receive, thus giving them greater control over their lives (Rees, 2008). This approach to service delivery has been trialled by the Australian Government in a consumer direct care initiative for aged care services (Gordon et al., 2012). An evaluation of this care initiative concluded that it was too early to determine whether this approach was cost effective and sustainable (Gordon et al., 2012). Another key finding from the evaluation was that despite being able to have a substantial self-management role in the delivery of the care package, patients and carers did not exercise this level of control. Gordon et al. (2012) suggested this related to a combination of personal and organisational factors, in that consumers lacked interest or had low self-

confidence, or were not given this option by the provider. While the objectives of consumer directed care aims to improve access to services for people with dementia by focusing on tailoring to patients' and family carers' needs, there are likely to be consequences for the organisations that provide support services. This approach assumes patients and carers play an active role in accessing support, which is more likely for those well functioning patients and carers and less likely for those with mental health concerns and other co-morbidities. Alongside consumer directed service implementation is an integrated system process, where organisations delivering care may require improved communication and information system management to collaborate with other services (Beeuwkes Buntin et al., 2006). Moving away from a system that is case managed by professionals and paraprofessionals, and towards a focus on consumer directed care and an integrated system approach is likely to bring about several organisational changes. These changes have the potential to impact upon workforce issues as well as quality care.

While organisational change theories offer some explanation for individual responses to workplace change and reasons for personal resistance, they do not necessarily help explain the up-take, acceptance and or dissemination of new innovations in care delivery. Innovation and translational research are relevant when considering how best to design innovations that will be readily accepted by workers in dementia care. Several attributes of innovations have been shown to influence the rate and extent of adoption by individuals (Greenhalgh et al., 2004). These included the relative advantage such as social prestige or convenience of the innovation, as well as the compatibility of the innovation to the individual and the setting which included similar values and beliefs systems. Other

important attributes of successfully implemented interventions included the relative complexity and trialability of the innovation such as how the rationale for the intervention was understood. In addition, how observable the results were to those involved was a key part of acceptability of innovations, as well as how well the program could be re-invented or changed by the user to suit the circumstance. Involvement of patients and carers in the design and implementation process of public services is also known as coproduction. Ottmann, Laragy, Allen and Feldman (2011) suggested that by following a coproduction approach there is potential to improve the quality and responsiveness of public services, which extends to include an increase in effectiveness of services and reduction in public spending, while also strengthening citizenship and democracy.

There are many reported problems in health service delivery, including the up-take of new services or interventions, particularly concerning best practice paradigms in dementia. However, for the marketing and technology setting where companies develop new products for sale, there is greater successes regarding the development and delivery of new products to market, in comparison to services within the health sector (Lomas, 2011). Perhaps health services can take some inspiration from businesses and the processes they follow to ensure low failure rates and success with translation. Collaboration across health care at all levels is vital for successful up-take of interventions. Too often in health care the domains of policy, research, dissemination and service delivery remain separated. Following processes adopted within the business setting where communication between design, manufacturing and consumers readily occur, may be relevant for dementia care to assist with acceptance of new interventions and translation of evidence into practice.

It is not only important to consider which strategies may be effective for capacity building, but also how these strategies have been devised in combination with the dissemination process of the strategies themselves. Lomas (2011) stated “perception rules reality when it comes to mapping innovation space” [Audio podcast]. Therefore, individual perception plays an integral role in the success of implementation of interventions, and what people see as the problems or the benefits of the intervention are likely to influence the dissemination message. To promote innovation spread, improvements in the “status quo” of an organisation are made part of the translation outcome, communication channels are open or created for potential adaptors (i.e., the target audience of the intervention) and dissemination networks and partnerships are primed to deliver and receive tailored messages of change (Lomas, 2011). For interventions to be accepted by the target audience a clear link between the creators of innovation and those receiving it is needed.

Innovation spread is about the co-ordination between the researchers and or creators, the dissemination specialists and the adopters or users of the innovation. Still being established, is how best to co-ordinate this area, and holds relevance for dementia care. Coproduction and innovation implementation assume that service delivery is informed by needs identified by a target audience, in this case people with dementia and their informal and formal caregivers. When devising ways to build capacity in dementia care it will be necessary to consider these principles. For this reason, the current thesis includes the perspectives of both formal and informal carers of people with dementia on current and future directions of service delivery. In addition, employee performance may influence the success the coproduction approach, and be related to employees’ reactions to

high job demands in dementia care. Thus, theories that inform employee performance in light of high demands at work will also be explored in the current investigation.

Job demands-resources model

The job demand-resources (JD-R) model (see Figure 1) offers a theoretical explanation for employee performance and turnover. The JD-R model purports that negative employee performance is the product of *job demands* exceeding *job resources*. Job demands refer to physical, social, or organisational aspects of the job that require sustained physical or mental effort. These efforts result in certain physiological and psychological costs (e.g., exhaustion and or burnout; Demerouti et al., 2001). Job resources are health protecting factors that contribute to and maintain worker well-being, even after encountering high degrees of workload. Job resources facilitate achievement of work goals, reduce job demands and their associated costs, and stimulate personal growth and development (Demerouti et al., 2001). Job resources may be placed at the level of the organisation (e.g., salary, career opportunities, and job security), at the level of interpersonal and social relations (e.g., supervisor and co-worker support, and team climate), at the level of the organisation of work (e.g., role clarity and participation in decision making), and at the level of the task (e.g., performance feedback, skill variety, task significance, task identity, and autonomy; Rothmann, Mostert, & Strydom, 2006).

In the JD-R model, worker withdrawal behaviours, such as absenteeism and turnover are explained as the consequence of lack of resources to aid worker coping and can result in burnout (Bakker, Demerouti & Euwema, 2005). Burnout is defined as a distressed psychological state that an employee might experience after being on the job for a long period of time (Specktor, 2008), which includes core

components of exhaustion and depersonalisation or cynicism. Initially burnout was derived to explain reactions of employees in helping professions, but was later applied to other work settings (Landy & Conte, 2007). Thus, when there is an imbalance between job demands and resources, workers' experience the psychological costs of their job roles, such as job stress or burnout, which has been found to predict absenteeism and worker disengagement or withdrawal (Bakker et al., 2005; Demerouti et al., 2001).

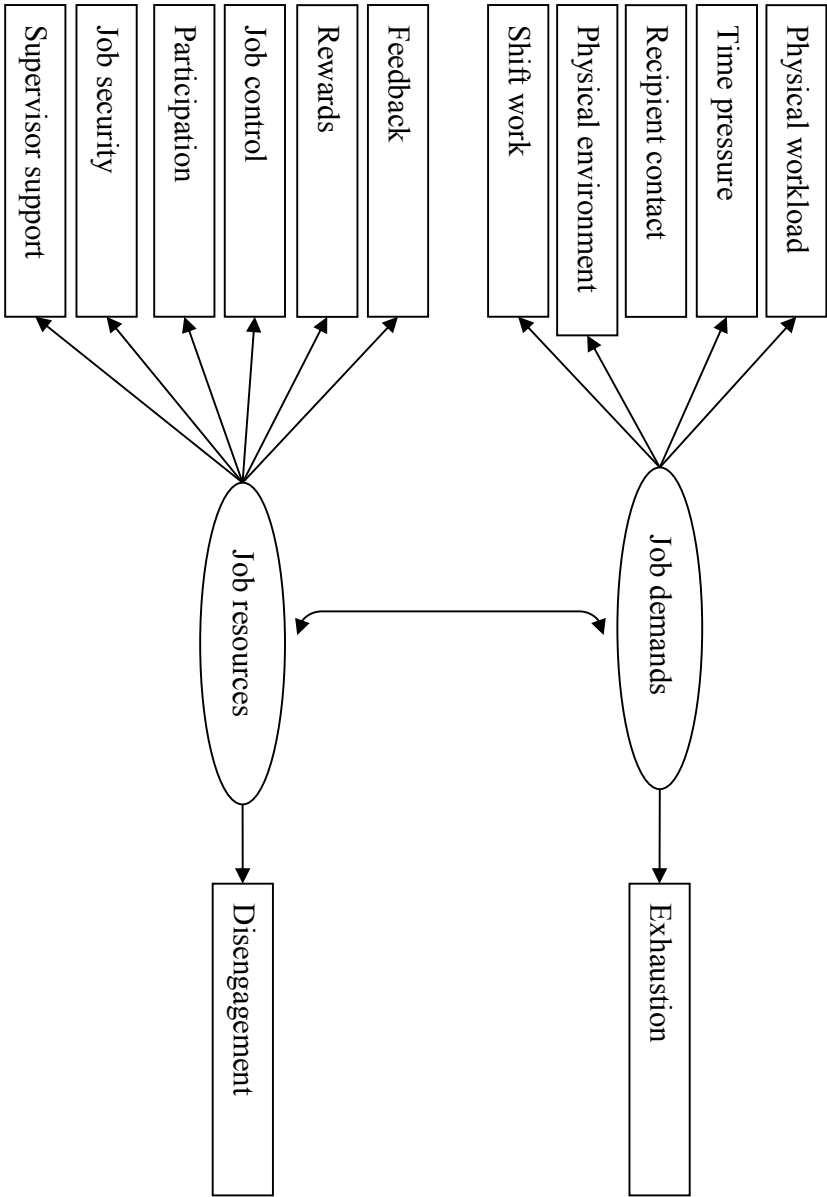


Figure 2. Job demand-resources model of burnout (Demerouti et al., 2001)

A considerable number of studies find aspects of the JD-R model predict physical and mental health of health care workers (Michie & Williams, 2003). However, the model does not adequately account for staff turnover and has mostly been tested with highly skilled, well educated health care workers. Further, the model does not consider employee values regarding their working relationship with the people they are serving or supporting (i.e., the consumers or care recipients). Workers' perceptions of, and satisfaction with the quality of their service provision and their working relationship with consumers might be important to consider. In an American cross sectional study, one of the main motivational factors for direct home care workers was their commitment to the consumer and this predicted commitment over and above workers' wages and socio-demographic variables (Howes et al., 2008). Examining whether the JD-R model applies to the dementia care workforce, with particular regard for organisational commitment and intention to stay at the workplace may allow for a unique analysis of capacity building with a focus on resources that may appear to bolster resilience in workers.

The complexity involved with caring for people with dementia may mean that there are job demands unique to the dementia care role. These demands may relate to the severity of dementia symptoms (i.e., delusions, aggression and sexual behaviours), the degenerative nature of the disease such as dealing with loss of identity and functional decline. Job demands for dementia care workers may also relate to the nature of the work such as working independently and entering people with dementia's homes to deliver care. Workers who experience poor well-being may not only have high demands but also perceive their access to job resources to be low. Job resources that are relevant for general health care workers such as those mentioned in Figure 1 may also apply for dementia care workers. It is likely that community dementia care

workers will experience insecurity and low level of remuneration, but whether this lack of resources is likely to affect workers (i.e., burnout, poor well-being, and job dissatisfaction) is unknown. Considering the psychological response of workers to their job roles may help identify barriers likely to interfere with the ongoing capacity of the workforce, to not only continue in their care roles (i.e., retention efforts), but also, to improve their skills and quality of service delivery. Job resources that facilitate positive employee performance may include organisational support from employees' workplaces. In this way, job demands and resources are closely linked to the concept of perceived organisational support, and may be relevant for service delivery in dementia care.

Perceived organisational support

Organisational support theory presupposes that in order to meet socio-emotional needs and to assess the benefits of increased work effort, employees form a general perception concerning the extent to which the organisation values their contribution and cares about their well-being (Aselage & Eisenberger, 2003; Eisenberger, Armeli, Rexwinkel, Lynch, & Rhoades, 2001). The social exchange view was used by Eisenberg et al. (1986) to form the notion of *perceived organisational support (POS)*, and as stated by McFarlane Shore and Tetrick (1991) "this view suggests that an employee's inferences about the organisation's commitment to him or her contributes to the employee's subsequent commitment to the organisation" (p. 1). Therefore, if organisations are to expect workers to take on new skills, and additional roles in the future, the perceived organisational support of regulated and unregulated health workers may play an important role in commitment to the job and subsequently intent to leave, however, this remains untested. Further, this remains untested in relation to the JD-R model of burnout and disengagement, as organisational variables

such as perceived organisational support have not previously been reviewed for dementia care workers in this light. Understanding the role of perceived organisational support may be one factor to consider in a model describing intent to leave and subsequent turnover for the dementia workforce.

Employees can have both positive and negative emotional experiences relating to their work, which can influence the level of effort they make towards daily job tasks. Expectations held by workers about the role the workplace has to play during times of high demand can also affect how they carry out their jobs. If workers have strong perceptions of organisational support then they feel an assurance that aid will be available from the organisation when it is needed to carry out one's job effectively and to deal with stressful situations (George, Reed, Ballard, Colin, & Fielding, 1993). A meta-analysis indicated that three major categories of beneficial treatment received by employees (i.e., fairness, supervisor support, and organisational rewards and favourable job conditions) were associated with POS and POS in turn, was related to outcomes favourable to employees (e.g., job satisfaction, positive mood) and the organisation (e.g., affective commitment, performance, and lessened withdrawal behaviour; Rhoades & Eisenberger, 2002). POS may play a role when organisations are undergoing change, especially regarding motivation for employees to meet increasing work demands. Concretely ensuring that procedures are fair and perceived as such by employees, showing recognition for employees' accomplishments, adapting work schedules to meet individual needs whenever possible, providing opportunities for professional development, enriching jobs and clarifying expectations are examples of ways organisations can influence perceptions of support (Panaccio & Vandenberghe, 2009). In the dementia care industry, improving factors associated with perceived organisational support of direct care workers (i.e., commensurate

remuneration), may be one strategy to improve capacity, however this is yet to be tested.

Whether or not workers are committed, engaged and willing to attend further training may also be related to POS. If organisations are able to offer support to workers to participate in training, attendance at conferences and other professional development opportunities this may in turn lead to workers positive perceptions of their organisation. Workers who feel supported by the organisation are often willing to put more effort into their job tasks, which could include participation in training. Dementia training interventions may include participation incentives that are linked to POS. These incentives may include covering the cost of training workshops and or paying workers for their time to attend training. The administration of such incentive programs would need to be open and clear to workers considering the importance of fairness in favourable employee outcomes (such as job satisfaction). Applying the principals of POS to dementia care may assist in providing new strategies for workforce engagement.

The perceptions that employees hold about their supervisors is also related to perceived organisational support. The role of the supervisor is to act as an agent of the organisation (i.e., assessing workers performance to ensure adherence to policy and procedure), and employees consider this role as an extension of organisational support (Rhoades & Eisenberger, 2002). In most cases, the supervisor has the authority to report in a favourable or an unfavourable light with regard to the employees' performance. Depending how this role is played can influence employees' general views on how supervisors' value employees' contributions towards work and value their well-being. The lower proportion of supervisors and managers in the dementia care workforce (in the United Kingdom; Hussein & Manthorpe, 2011) compared to

other health services may therefore have an effect on care workers' level of POS and subsequent capacity issues. Supervisors may play an important role in capacity building. Whether or not supervisors are able to balance their regulatory role on behalf of the organisation against their supportive role to help guide employees is likely to influence POS of the workforce. How workers perceive the support from their supervisors may influence their level of engagement with the organisation and subsequent work efforts they expend. If there is to be a motivated and engaged workforce, organisations need to show workers they care for workers interests. Investigating current ways dementia care workers feel supported by their organisations may assist in developing capacity building strategies for the future.

Person-organisation fit

The person-organisation fit theory (P-O fit; Kristof, 1996) focuses on employee values, though not in regard to their satisfaction with consumer relations. Rather, P-O fit purports that the extent of congruence between the values of the organisation and its employees predicts the effectiveness of organisations (O'Driscoll, Taylor, & Kalliath, 2003b). Good P-O fit predicts increased job satisfaction, morale, organisational commitment, quality of life, personal well-being and reduced turnover (Becker & Billings, 1993; Lauver & Kristof-Brown, 2001; Vandenberghe, 1999; Verquer, Beehr, & Wagner, 2003). However, the application of P-O fit theory to assist organisations to manage change is not well investigated. It is hypothesised that if organisational goals are shared by the worker and the organisation, this congruence may not only contribute to a healthy workforce, but may also act as an enabler in preparedness for organisational change.

Since the industrial revolution the organisation and nature of work has undergone severe changes. The development of unions, where a collective

organisation of people formed to advocate for better working conditions, has led to a more advanced concept of employee choice. Legislation on employment conditions that protect the rights of workers to have fair treatment and pay conditions are well established in most countries across the globe. In a society where access to skilled workers is becoming limited, employees have choice, and often consider working for organisations that suit their work-life preferences. In this way, P-O fit has become an increasingly important aspect of the employment relationship, as good P-O fit has been linked to organisational attraction and retention, recruiters' selection decisions, and employees' work-related attitudes and actions (Resick, Baltes, & Shantz, 2007). There are two distinct types of P-O fit that depend on the way this concept is assessed. Objective fit involves gathering separate information about the person and the organisation, then assessing their congruence, whereas perceived fit involves asking people directly whether or not they believe they are a good fit with an organisation and its members (Resick et al., 2007). P-O fit can extend to include how similar workers' perspectives are on workplace matters, in particular which organisational factors are important in comparison to other less important aspects of work. A holistic view of P-O fit captures both the person's congruence with an organisation's culture and members. Community dementia care workers undertake care tasks independently and interact mostly with the people they care for, and therefore it is unknown whether P-O fit applies to the dementia care workforce and what role it may play when organisations are undergoing innovation transition.

While P-O fit has not previously been explored in the dementia care workforce, it has been applied to staff outcomes in services for people with disabilities (Hatton et al., 1999). Employees in the disability services setting reported an ideal organisational culture included high staff rewards, tolerance and orientation

towards staff, and fostering social relationships with colleagues as well as low work demands (Hatton et al., 1999). While the study by Hatton et al. (1999) included all employees in the organisations delivering support services (such as, managerial, administration, “frontline” and cleaning staff), the findings may still be applicable for workers in dementia care. The disabilities and aged care sectors in Australia often cross over in responsibilities (i.e., HACC) and the supportive care tasks of frontline workers share similarities. This study also highlights the potential for there to be a relationship between P-O fit and communion (introduced later in this chapter), as social relationships were perceived by disability service workers as integral to the ideal organisational culture.

Workers’ formation of their congruence with an organisation can occur on several levels. The match of the worker to their work colleagues, sometimes known as *person- work group (P-G)* fit, may moderate workers’ attitudes and perceptions on organisational congruence. Worker’s suitability to perform certain job-related activities and daily work tasks, known as *person-job (P-J)* fit can also contribute to organisational congruence. In most roles P-J fit is determined by career choice and years of education and training and are evident through the employment process (i.e., during recruitment and selection, as well as while on contract; Jansen & Kristof-Brown, 2006). In contrast, P-G fit may only become realised after recruitment and is not as strongly related to job satisfaction as P-J fit (Kristof-Brown, Zimmerman, & Johnson, 2005). Further, in the dementia care setting P-O fit may involve some type of extension of fit between the worker and the client, as job tasks relate heavily to personal care where intimate interactions take place, however this extension of P-O fit is hypothetical and requires further investigation.

The connection between personal and job characteristics are also part of the P-J fit. Knowledge, skills, and abilities (KSAs) needed to perform the task-related demands of a job (known as the demands – abilities; D-A job fit) and the extent to which a job's characteristics and rewards fulfil a person's psychological needs or preferences (the needs-supply; N-S job fit; Edwards, 1991) form part of the person-job fit. One of the strongest predictors for job satisfaction is how a worker's personal and psychological needs are fulfilled by a job (Kristof-Brown et al., 2005). The intrinsic personal motivators for joining the dementia care workforce remain relatively unexplored and may relate to the perceived knowledge and abilities of workers. Further, this may have implications for recruitment innovations, as people with previous experience in personal care may be drawn to work in the dementia care area. Closely related to the match between worker and personal values, are the personal factors that motivate or help to define employee behaviour. Clinical and social psychological perspectives can offer several explanations for human behaviour that may apply to the work setting.

Clinical Psychology

Self-efficacy

Clinical psychology is a sub discipline or specialty of psychology and may be defined as the application of the principles and procedures of psychology to health care (Martin & Brinbraue, 1996). It is an integration of science, theory and clinical knowledge for the purpose of understanding, preventing, and relieving psychologically-based distress or dysfunction and to promote subjective well-being and personal development (American Psychological Association; APA, 2012). Clinical psychology can be applied to many health care settings, extending to people with mental health or medical disorders, their carers or family, or to employee

health. There are many theoretical approaches within the clinical psychology literature, one of these is the *self-efficacy* theory (Bandura & Adams, 1977). Self-efficacy is the belief in one's own ability to successfully accomplish something (Hayden, 2009). The role of self-efficacy in the dementia care workforce may have implications for strategies used to build capacity in the sector. Workers who experience confidence in their abilities may find facing challenges of increased workloads easier to manage than those with poor self-efficacy.

Self-efficacy is a construct of *Social Cognitive* theory, and Bandura (1988) stated "social cognitive theory explains psychosocial function in terms of triadic reciprocal causation. In this causal model, behaviour, cognitive and other personal factors and environmental events all operate as interacting determinants that influence each other bi-directionally" (p. 275). It holds true that self-efficacy and social cognitive theory are both relevant for learning and skill acquisition. Self-efficacy influences the likelihood that an individual will accomplish a certain task and the theory presupposes that people generally will only attempt endeavours they believe they can accomplish and will not attempt endeavours they believe they will fail. However, people with a strong sense of efficacy believe they can accomplish challenging and difficult tasks and in this instance challenges are often sought out to be mastered rather than avoided (Hayden, 2009). If dementia care workers are not seeking to attend further ongoing training (such as in the Australian example; Doyle et al., 2009) then perhaps some workers may have perceptions of low self-efficacy specific to learning and education that act as a barrier to capacity building.

There are many ways that self-efficacy is developed, including direct mastery experiences where individuals can learn skills and gain comprehensive understanding through practice. Social comparison also influences self-efficacy

where individuals perceive their likelihood of achieving vicariously through another person's experience (Maddux & Stanley, 1986). The success of building self-efficacy in this instance relates to the individuals' perceptions that they are similar to the person they are observing. Social persuasion in the form of encouragement or discouragement and attributional evaluations, as well as emotional arousal (Bandura, 1986) also influence self-efficacy, which has implications for communication in the workplace and management or supervisory feedback. Consideration of the varied ways self-efficacy can be altered may be required to form capacity building strategies for the dementia care workforce, particularly in light of overcoming barriers of access to education and training. It may also be relevant for building a culture of learning and ongoing professional development, where workers perceive themselves and others as capable and competent in the face of new challenges.

Cognitive appraisals of work events can influence the physical and emotional state of an individual, in turn effecting perceived self-esteem. The individuals' level of arousal that occurs when someone deliberates about performing a task can influence the successful completion of that task, therefore self-esteem can be negatively affected by symptoms of anxiety which can lead to a self-fulfilling prophecy of failure (Bandura, 1986). While modelling with guided practice is a highly effective method for developing skills and competencies, following this logic, skill acquisition is likely to be affected by the emotional state the individual is in during the time of learning and practice. Bandura (1988) stated that:

There is a difference between possessing skills and being able to use them well and consistently under difficult circumstances. Success requires not only skills but strong self-belief in one's capabilities to exercise control over events to accomplish desired goals. People with the same skills may,

therefore, perform poorly, adequately, or extraordinarily, depending on whether their self-beliefs of efficacy enhance or impair their motivation and problems-solving efforts (p. 279).

Performance on job tasks is directly influenced by how dementia care workers think about their own capacity to effectively complete their roles. The way workers perceive high care demands such as dealing with the degenerative nature of dementia, and time pressured workloads may affect the emotional responses of workers. If workers perceive that they cope well, then they may approach new tasks or requirements (i.e., training) as a challenge. However, if workers have negative self-perceptions, then this is likely to interfere with their readiness to learn and take on new job tasks, perhaps leading to avoidance behaviours. Further, in a job where care tasks are complex and difficult, (i.e., care recipient behavioural changes), self-efficacy can play a role that may either help or hinder performance. Highlighting the nuances that can assist dementia care workers to be confident in the face of additional work demands may assist in developing capacity building strategies.

More broadly, in the clinical psychology literature, self-efficacy (or confidence) to meet demands on coping resources predicts better adjustment to a range of chronic stressors (Turner, Holtzman, & Mancl, 2007). Intrapersonal variables might aid employees coping, such as coping self-efficacy, life satisfaction, work knowledge and training. Occupational stress mainly focuses on the domain of work, however to gain a full understanding of the capacity of a worker it is also necessary to take into account stress from other domains, such as their experience of emotions both inside and outside of work. Assessment of workers' experience of positive and negative emotions may also allow for further appraisal of workers' readiness to learn and participate in training or capacity building interventions. It

may be that a proportion of workers will benefit from learning stress management and coping strategies, or that resilient workers can offer suggestion of strategies to cope in a high demand work environment.

Role ambiguity and emotional labour

Role ambiguity and role conflict are common constructs investigated in the organisational setting, and have connections with job stress (Noblet, Graffam, & McWilliams, 2008). Role ambiguity refers to the extent to which employees are uncertain about their job functions and responsibilities (Specktor, 2008). Role conflict arises when people experience incompatible demands either at work or between work and non-work (Specktor, 2008). Both role conflict and role ambiguity are thought to play a part in workers' stress appraisals and subsequently may have links to retention and turnover issues. Stressors refer to environmental demands with which individuals feel unable to cope (Lazarus & Folkman, 1984). A meta-analysis of seven work related stressors (role ambiguity, role conflict, role overload, job insecurity, work-family conflict, environmental uncertainty, and situational constraints) and their relationship to job performance was conducted (Gilboa, Shirom, Fried, & Cooper, 2008). Work related stress and job performance were found to be negatively associated with role ambiguity and situational constraints, and when worker characteristics such as managerial status was taken into account, role overload was negatively associated with performance more so for managers than non-managers (Gilboa et al., 2008). Job stress mediates performance. In particular, employees' lack of knowledge of what is expected of them in their daily job tasks constricts their ability to meet job expectations and in turn leads to negative emotions. In the community-based dementia care setting, role conflict may relate to confusion over expectations in different clients' homes. Therefore, an expansion of

dementia care workers' roles may need to be approached carefully to ensure workers have sufficient knowledge and levels of confidence in new tasks as to avoid potential job stress.

The ways in which an organisation approaches new and challenging initiatives may influence employees' experience of role ambiguity and job conflict. In particular, workers employed by organisations that encourage and reward employees to adopt new initiatives may perceive job ambiguity as a challenge to overcome. Whereas workers employed in organisations that emphasise standardised operations and reward performance based on the pursuit of well established processes and procedures, role ambiguity may be more likely to be perceived as a threat (Gilboa et al., 2008). Individual worker differences, such as whether or not they perceive role ambiguity and role conflict as a threat, or a challenge, may influence their commitment and intent to stay. Employees who have high tolerance for ambiguity are more likely to perceive a potentially stressful situation as a challenge rather than a threat, compared to individuals with lower tolerance for ambiguity (Giloba et al., 2008). This has implications for capacity building interventions as it highlights an approach could include targeting elements relevant to both the individual worker and the organisation, such as building tolerance for ambiguity and adopting an approach that rewards involvement in new and challenging initiatives.

The regulation of emotional expressions and feelings as part of the paid work role is known as *emotional labour*, which occurs when expected workplace emotions cannot be naturally felt or displayed, and is routinely performed using *surface acting* and *deep acting* (Hochschild, 1983). In the United States and Europe, more than two thirds of the already growing labour force is part of the service sector (Hülshager & Schewe, 2011). Employees in the service sector participate daily in personal

interactions and experience emotions they can choose to display or hide. Dementia care is no exception, with the main job roles relying on interacting with people with dementia and their family members or friends. Surface acting can involve deceiving others about the true emotional experience and often includes faking emotions not felt and suppressing and hiding feelings that are deemed inappropriate to display (Kiely & Sevastos, 2008). For example, a dementia care worker may hide feelings of frustration or anger in response to a person with dementia's symptoms such as cognitive impairment resulting in the care recipient repeating questions throughout the care shift. In this example the worker is motivated to not express their true emotions so that they do not alarm or further confuse the care recipient.

The converse of the surface acting experience is deep acting, which Kiely and Sevastos (2008) described as “the intrapsychic process of attempting to experience or alter feelings so that expected emotional displays may naturally follow” (p. 16). Deep acting is a strategy used to manipulate one's emotional response for the benefit of the work environment. Deep acting occurs before the behavioural response associated with an event that is experienced (i.e., tight lips, red cheeks and wrinkled brow of anger). Gross and John (2003) suggested that deep acting is an antecedent-focused form of emotion regulation. In deep acting the awareness and processing of emotional cues are affected by changing the perception of a situation. An example demonstrating this is when flight attendants were trained to cognitively reappraise challenging adult passengers as children so as not to become distracted by their behaviour (Hochschild, 1983). By focusing on thoughts of images or memories that induce a desired emotion, workers were able to use a strategy of deep acting similar to actors trained using the *Stanislovsky* method, a technique which has been found to produce an authentic display of emotion (Kiely & Sevastos, 2008). This might

involve a worker thinking of a funny experience or situation so she or he can express an appropriate reaction to a care recipient's shared humour. When engaging in deep acting, individuals try to align required and true feelings (Hülshager & Schewe, 2011). Considering dementia care workers are part of the service industry, logically it would appear they experience emotional labour. However, it is unknown if there are common patterns of how workers use surface and deep acting in their job roles, in light of the intimate nature of personal care tasks. Further, there may be additional domains relevant for emotional labour, in particular how workers cope with communication about degenerative disease and terminal illness.

There are consequences associated with emotional labour, often involving some form of role conflict for the worker. *Emotion-rule dissonance* is a term used to describe a particular form of person-role conflict where incongruence exists between the actual emotions and the emotions that are required for display rules, often resulting in unpleasant state of tension (Hülshager & Schewe, 2011). The difference between emotion-rule dissonance and deep and surface acting relates to the processes at play. While emotional-rule dissonance is an experienced state, surface acting is a strategy used to manage emotional regulation. Positive and negative consequences are associated with emotional labour. However emotion-rule dissonance often results in personal strain. A double edged sword exists, where Hülshager and Schewe (2011) stated:

Employees can either over rule their own values, adhere to organisational display rules and thereby threaten their sense of authenticity, or they can hold on to their personal aspirations, disregard their professional duties and run the risk of dissatisfying customers and supervisors (p. 365).

In most cases emotional-rule dissonance helps to avoid conflict, but at a cost, as employees experience stress and their personal resources are threatened. Impaired well-being is associated with emotion-rule dissonance and surface acting, and less so with deep acting (Hülshager & Schewe, 2011). Further, emotional regulation strategies mediate the connection between emotion–rule dissonance and well-being and performance. Personal resources factors that contribute to managing stress associated with emotional labour may form part of the capacity building picture in the dementia care workforce, and serve to prepare new workers and or existing workers to deal with the high demands of the job associated with service delivery. Processes involved with customer service may differ across occupational domains, with differences between hospitality and health care. Additional or unique strategies may be adopted by dementia care workers that extend the current theoretical literature on the role of emotional labour in health care settings. One of the main similarities between the human services and care delivery sectors is that they both comprise social systems. Thus, the social psychological perspective is also relevant for emotional labour and role ambiguity.

Social Psychology

Communion

The concept of communion originally coined by Bakan (1966) may apply to the dementia care workforce, due to the social nature of care work and the subsequent roles and duties performed as part of the role. A sense of communion, which refers to a person's desire to closely relate to, co-operate and merge with others, where individual fulfilment is experienced through relationships and a sense of belonging (Guisinger & Blatt, 1994; McAdams, 1993) may be relevant for the care context. Bakan (1966) postulated that communion and *agency* were two fundamental

modalities of human existence, with agency referring to the individual need for control, personal achievement and autonomy (Li, Tseng, Wu, & Chen, 2007). While Helegon (1994) argued that communion is a broad personality trait, Marszał-Wiśniewska and Siembab (2012) suggested that nurturance and dependence are an integral part of this concept. Communion may offer an explanation for care workers' high commitment to their roles (known to be based in commitment to clients over and above wages; Howes et al., 2008) and have implications for recruitment strategies for future workforce participation.

Gender differences have often been associated with the social psychological theory of agency and communion, where communion is more likely to be associated with femininity, and agency with masculinity (Helgeson, 1994). Considering that one of the main characteristics of care workforces internationally is a majority of female employees (Martin & King, 2008; Montgomery et al., 2005; Smith & Baughman, 2007; Yamada, 2002) communion may have particular relevance for this setting. A balance between the two modalities has been found to have implications for psychological functioning and extreme forms of communion such as *unmitigated communion*, where "a focus on and involvement with others to the exclusion of the self" (Helgeson & Fritz, 1998, p.173) is central to poor psychological health (i.e., depressive symptoms in women). Therefore, communion may be particularly important for dementia care workers' psychological functioning.

Communion has previously been applied to the business setting, in relation to career development and corporate social responsibility. In particular, Marshall (1989) drew parallels between the notion of communion with trust and acceptance during the development of one's career. Others have shown a particular interest of the application of communion to the female career, and argued that balancing

communion with self-driven interest and control (agency) was central to career development of females (Arthur, Inkson, & Pringle, 1999; Pringle & McCulloch-Dixon, 2003). Further, Ellery-Brown (2011) argued that in sharp contrast to men, women's career histories were relational and linked to personal development, which may apply for the dementia care workforce.

The notion of communion was included in a discussion about the definitions of corporate social responsibility and sustainability (Van Marrewijk, 2003). When multinational companies over emphasised their self-preservation and ignored their participatory role within the community, it was argued that social disintegration was created (Van Marrewijk, 2003). In this context, the role of communion was perceived as a way to promote sustainability of corporate organisations, by avoiding disengagement from clientele who perceived the company as self and not others focused. By promoting communion in a company the reverse may be true, where clientele engage and help to sustain an organisations' longevity. Therefore, the nature of an employer's agenda and service directive may influence organisational performance, with communion suggested as a positive influence on sustainability. While communion appears to be relevant at the worker level, it may also be relevant at the organisational and systems level. Whether or not a focus on communion is adopted by support services delivering care to people with dementia may influence organisational functioning and sustainability.

Another study found that communion striving resources (such as social interaction with colleagues) was associated with emotional exhaustion in fire-fighters (Halbesleben & Bowler, 2007). This study demonstrates communion has another positive role to play. In this sense, communion in the work context may serve as a protective factor at the employee level, buffering worker negative well-being such as

burnout. Whether or not the same is true for dementia care workers remains unknown. Despite these studies, little research has focused on the application of communion to the paid caring role. It may be that the social relationships integral to the caring role create a sense of interconnectedness between the care worker and their clients' lives. This social connection may be developed or hindered depending on the nature of caring interactions, and may also influence a sense of belonging professionally and may play an important role in attraction to the care sector and work commitment.

Methodological and Ethical Approach

The thesis employs a series of studies to investigate capacity building and resilience for the dementia care workforce. Each study in the thesis follows a separate methodology, however they are closely connected. While the series of studies collectively aim to broaden the view of capacity building, they present a unique contribution in a defined research area. Therefore, certain methods are followed that suit the particular aims of each study. In this subsection, the methods adopted within each empirical study are briefly described, with more detail presented later in the thesis. Study 1 reported in Chapter Four, employed a systematic literature review to conduct an analysis of effects sizes and methodological rigor of dementia training interventions. Study 2 is reported in two parts (A and B) in Chapters Five and Six. Study 2 employed a mixed methods analysis of the same sample of participants. Study 2 – Part A adopted Interpretive Phenomenological Analysis (IPA; Smith, Flowers, & Larkin, 2009) to explore qualitative data. Whereas, Study 2 – Part B employed a case-based clinical psychology approach to review quantitative data. Study 3 presented in Chapter Seven reports the findings from another mixed methods inquiry for a separate group of participants, where qualitative and quantitative data

were analysed independently and then compared and discussed. As mentioned previously, each method is described in more detail within the empirical research chapters of the thesis.

The empirical research that is reported in Chapters Five, Six and Seven underwent an ethical review process. This process included an initial phase completed within the University of Tasmania to determine the level and nature of risk to participants. The initial phase included the presentation of a research proposal and plan. These were presented to a research colloquium within the School of Psychology and also submitted to the Graduate Research Department at the University of Tasmania. The research proposal and plan were granted approval by the School and the Department, in September 2009. Following the initial phase, it was determined that an ethics approval must be sought from the Tasmanian Health and Medical Human Research Ethics Committee, as the research would be collecting personal information from staff and patients of community health and hospital services. A National Ethics Application Form (NEAF) was completed and approved by the Tasmanian Health and Medical Human Research Ethics Committee, EC00337 (reference number H10984) prior to recruitment.

Completing the NEAF determined that there were minimal risks to participants, as participants would undergo interviews, complete measures or participate in a discussion workshop that were designed to ensure that burden to participants was minimised. The progress of the project and recruitment was monitored by the Candidate's supervisor, Dr Jenn Scott, during regular fortnightly meetings from September 2009 – August 2012. Recruitment procedures were developed that ensured participation was voluntary and participants were provided with detailed information about their involvement prior to consenting to participate.

All participants were informed they could withdraw from the research at any time, without effect to their relationships at work or care from health services. Following the process described above ensured that the research conducted in the thesis complied with the National Statement on Ethical Conduct in Human Research (National Health and Medical Research Council & Australian Research Council, 2007). Further details of the ethical considerations are presented later in the thesis, in the respective studies.

Limitations of the Research

Studies that report null results tend to be unpublished. Thus, the systematic literature review (Study 1) may have an in-built bias towards positive and significant results. There may be an over representation of positive results in Study 1, which is a problem many systematic reviews acknowledge (Higgins & Green, 2011). The review focused exclusively on studies that assessed both worker and organisational variables and was therefore highly focused. While a limitation of Study 1 is the focused nature of the review, combining both worker and organisational outcomes to determine capacity factors relevant for workforce development was considered necessary to determine the sustainability of training outcomes.

There may be problems with the generalisability of the findings of Study 2 to the broader dementia care worker population as the sample was small and the majority of participants were female. Study 2 adopted a small selection of the community-based dementia care workforce in Tasmania, an island State of Australia. Study 3 was also based in the same location but investigated a small proportion of informal dementia carers, with generalisability of results to the wider caregiver population also considered a limitation. Tasmania is the 26th largest island in the world, but it has a relatively small population of just over 500,000 people (ABS,

2012a). There is expected to be a higher proportion of clients accessing community home care in Tasmania than any other Australian State or Territory (AE, 2010).

Further, island communities, like Tasmania, and regional areas are particularly vulnerable to workforce shortage, (ACG, 2007; DCAC, 2009) and experience concerns with multi-discipline competency (Booth et al., 2005). Further, for Study 2 and 3 convenience samples were employed whereby self-referral occurred.

Therefore, most workers experiencing burnout and actively contemplating leaving the sector may not have participated. Similarly for informal caregivers this minimised the likelihood of recruiting carers that were experiencing depressive symptoms or not engaged with a community service provider, which are common problems for research in the field. There are likely to be differences between participants who have high or low motivation to participate in research, which may be another limitation of the series of studies in the current investigation.

The results of the series of studies may be influenced by the low number of participants, particularly for the quantitative analyses. Caution is noted when using subscales on psychological measures, as the uses of subscales can increase the likelihood of type II errors. This may apply particularly for the case-based clinical psychology analysis of Study 2- Part B. A lower proportion of males were recruited in Study 2 and 3, which may be considered a limitation. The themes identified for the qualitative studies reported in the current investigation may be more representative of the female carer, and less so of the male carer. Thus, a limitation of Study 2 and 3 may be that distinctive features of the male caring role were under represented. While there were relatively lower proportions of males in the current series of studies, no comparisons based on gender took place, and gender difference was not a primary interest of the current investigation. In addition, most studies in the area of paid care

work or informal care follow a similar pattern where there is a majority of female participants (Martin & King, 2008; Montgomery et al., 2005; Smith & Boughman, 2007; Yamada, 2002). This limitation may influence the findings of occupational communion, as it may be that this concept is partially relevant for women's caring carers, and the application of occupational communion to men's professional caring careers may require further investigation.

While the current series of studies attempted to offer a coproduced view (involvement of consumers in the design and implementation process of public services), by reviewing the perspectives of both formal care workers and informal carers, no organisational perspective was presented from managers, and may be considered for future research. The same was true for the perspective of the person with dementia. However, the current series of studies did include the consumer voice by investigating informal dementia carers, who represented their personal perspectives and also provided information on the needs of their care recipients. Further, P-O fit was observed from the workers' perspective. Undertaking a more objective view of P-O fit may have offered confirmation that when workers described the goals of their workplace these were corroborated with mission statements. However, perceived P-O fit is still considered a valuable approach within the organisational psychology literature (Resick et al., 2007).

Conclusion

Organisational psychology theories in the human resources literature consider organisational culture such as the inter-group dynamics and behavioural aspects of work, while also taking into account the individual ways workers respond to and cope with change and transition in the workplace. Organisational theories have been applied to the hospitality, human resources and general health settings offering

several well validated approaches to improve turnover and work stress. Whether or not the same approaches apply for the dementia care setting where workers have low levels of education and training to deal with the multi-faceted and complex care needs of people with dementia is unknown.

Innovation success in health care hinges not only on the efficacy of the intervention or training but also on the employees response and acceptance of the intervention, therefore, considering how to engage the dementia care sector in capacity building approaches is paramount. Further, the flow on effects to the adopters of the intervention (i.e., patients and carers) is often determined by the degree to which the results are observable and the message is tailored to the audience. Considering both the formal and informal carers perspectives on service improvement and development will allow not only for well-rounded strategies, but also help to deliver a tailored and coproduced message integral to future service integration. In summary, a tri-theoretical approach will offer useful insight into the readiness of the dementia care workforce to receive capacity building interventions, and what those interventions may resemble.

A match in high job resources and high job demands (JD-R) may demonstrate positive worker well-being and retention, whereas an imbalance between job resources and job demands may contribute further to retention problems. Examining job demands and resources specific to the dementia care experience may highlight unique capacity building factors and offer insight to enhance organisational operation. Perceived organisational support (POS), where workers feel the organisation is caring for their well-being and work needs, may lead to a committed workforce ready to face challenges. Workers' motivational factors may extend to include not only a focus on care provision, but also on fair treatment of workers and

work issues, as well as appropriate remuneration. While the congruence between worker and organisational values (as described by the P-O fit theory) may assist the workforce to be prepared for future demands and organisational changes, it may also relate workers' organisational commitment and intention to stay. The application of P-O fit to the dementia care sector may highlight that a workforce interested in the future direction of their organisation performs well under challenging work situations. This positive worker adjustment may occur as the employee has access to organisational knowledge that may be reassuring during transitional changes. Thus, a workforce with clear direction and matching workplace values will show strong organisational commitment and intention stay, as the experience of role conflict is lower due to adequate workplace and job role knowledge. Self-efficacy or confidence to cope, and approach not avoid challenges, as well as using processes such as emotional labour in the face of complex care delivery may further contribute to an effective and prepared workforce. Adequate emotional regulation strategies and caring knowledge to deal with the complex needs of people with dementia, such as challenging behavioural symptoms, as well as ongoing issues of grief and loss related to the degenerative nature of the disease, are likely to contribute to a resilient workforce, ready to "bounce back" to difficulties associated with the care role, or the system their service operates within. An examination of whether or not communion in the occupational setting is relevant for the majority female dementia care workforce may determine the relevance of social relationships in the capacity building sphere.

The interplay between organisational, clinical and social psychological concepts may offer unique explanations relevant to dementia care, that identify enablers and barriers for innovation in service delivery. Therefore, the current thesis

will firstly investigate the efficacy of current care innovations related to training dementia carers. Particularly, to evaluate what the highest level of evidence can offer dementia training interventions in this sector. This evaluation is reported in the following chapter (Chapter Four) and describes Study 1, which adopts a systematic review. Secondly, the current thesis will include an in-depth qualitative review of dementia care workers' perceptions of key vocational domains, with a focus on the relational aspects of the care role (Study 2 – Part A). This focus will help to determine workers' response to the future of dementia care and readiness for intervention and is presented in Chapter Five. Thirdly, the current investigation will adopt a clinical psychology case-based approach to determine individual factors that relate to resiliency in dementia care workers (Study 2 – Part B). This approach will also highlight potential areas for intervention and will be presented in Chapter Six.

Finally, whether or not informal and formal carers align on their views of current and future dementia care service delivery will help identify similarities and differences unique to carer type (Study 3 presented in Chapter Seven). By conducting a multi-levelled investigation, a detailed analysis can be made to determine the translational aspects of dementia care services research. This approach may also suggest unique methods on how to begin collaboration within health services to allow for innovation spread and coproduction in dementia care. An overall discussion of the series of studies of the current investigation will be presented in Chapter Eight, and a list of recommendations for capacity building for dementia care will be presented.

Chapter 4

A Systematic Review of Dementia Training Interventions Targeting

Worker and Organisational Outcomes

(Study 1)

“Our industries require more flexible training packages that are current and reflect the fast-changing client-delivery practices”.

A comment made by Chris O’Brien, Chair of the Australian Community Services and Health Industry Skills Council, June (2011, p.2).

Dementia currently has a major impact on every health and social care system in the world (Wimo & Prince, 2010). A significant issue is the direct costs associated with care provision by health professionals. This economic burden is expected to worsen as the estimated number of people living with dementia is predicted to treble by 2050, to 115.4 million worldwide (2010). To avert a health care crisis, most developed countries have devised national dementia action plans or frameworks (Benbow & Kingston, 2010). Without exception, each nation declares that it needs to find ways to support and bolster their dementia care workforce to adequately withstand and confidently surmount the challenges posed by dementia in the 21st century (Australia's National Framework for Action on Dementia, 2006; American Alzheimer's Study Group, 2009; Canada's Rising Tide, 2010; England's National Dementia Strategy, 2009; Norway's Dementia Plan, 2007). At a political and public policy level, preparation is underway to best find ways to deal with the dementia epidemic. Whether this translates to current research evidence in capacity building for dementia care is yet to be determined.

This review aims to assess the current level of evidence on how dementia care worker training initiatives affect organisational capacity, through factors such as retention and service delivery. A comprehensive approach is taken to the examination of training interventions for workers in the dementia care setting. There is a bi-directional relationship between worker variables, (i.e., well-being, job satisfaction and functioning) and organisational climate or health variables (i.e., performance, productivity, capacity, or resilience, at the level of the organisation or workplace; Rafferty & Griffin, 2004). Therefore this review focuses on studies that can inform knowledge about the processes that are essential in this interaction. Dementia training interventions set in both primary

care and community health arenas will be included in the current review. Practical elements of training interventions for dementia will be detailed by focusing on information about the format of training and qualifications of facilitators along with the type of work setting and health care workers targeted by the training. Differing intervention components will be reviewed paying attention to whether or not organisational support components form part of the training as well as how the impact of these components is assessed. An aim of the study is to evaluate the applicability of training as part of capacity building in preparation for organisational change in the face of the ageing population trend.

The dementia care setting is made up of health and community services that are delivered within primary care, in-patient hospital care and residential nursing home, as well as community care. Barriers to high quality dementia care are linked to workforce issues and include workers limited knowledge of the disease itself, with low numbers of staff receiving dementia care training, even amongst those working in specialist dementia services (All Party Parliamentary Group, UK, 2009). Although training alone is insufficient to improve the care provided to people with dementia, the very low level of training in dementia is a significant barrier.

Currently this workforce is under siege. Demand is growing for care-givers, especially in community based settings as care workers are one of the occupational groups with the largest projected job growth this decade (Hecker, 2005). In Australia, the majority (83%) of care workers are based in the community, are female and 50 years of age (Martin & King, 2008). Very low numbers of care workers enjoy the benefits of full-time work, and it is most likely that they be employed under permanent part-time contracts (Richardson & Martin,

2004). Other nations, such as the United Kingdom and the United States share similar care workforce characteristics including low levels of education, qualifications and remuneration (Figueriredo, 2011; Hussein & Manthorpe, 2011). Financial constraints of care workers will limit access to training, a fate uncondusive to developing capacity in the workforce.

There is a lack of clear regulation status linked to heterogeneity of qualifications and training amongst the care workforce that results in poor employment terms and conditions and lack of career opportunities. This contributes to a high staff turnover due to poor recruitment and retention of dementia care workers (APPG UK, 2009). This workforce also faces problems of multi-disciplinary dementia competency in rural and remote areas worldwide (Morgan et al., 2011).

Health services research has focused extensively on topics related to attrition and staff turnover. Aged care, especially the dementia care labour sector is no exception to these investigations. There is a need for an aged care workforce strategy to recruit and retain workers with dementia knowledge and experience. A systematic literature review found the main reason for quitting the dementia care labour market was lack of job satisfaction, largely relating to negative worker appraisals of the quality of care provision (Vernooji-Dassen et al., 2009). Workers commonly reported feeling dissatisfied with the quality of care they were able to provide. Worker dissatisfaction may play a role to inhibit capacity building considering the negative effects of staff turnover. The lack of specific knowledge of dementia and ways to manage behavioural aspects of the disease may also contribute to job dissatisfaction in the care worker population. Care workers'

frustrations may arise from unresolved problems they feel underprepared to handle.

Review studies often report training interventions that take place in residential and or long-term care facilities (Kaasalainen, 2002; Kuske et al., 2007), leaving a knowledge gap about studies taking place in the community setting. There has been one published review of staff training in dementia interventions that was dementia specific. The review focused exclusively on nursing professionals working in nursing homes caring for dementia patients and included non-controlled trials, as well as randomised interventions (Kuske et al., 2007). They did not examine whether organisational variables were assessed as outcome measures.

In comparison to patient and informal care-giver outcomes, worker and organisational outcomes are often overlooked and until recently, organisational support and training evaluation literature received relatively little attention. In particular, the impact of training and education on levels of job satisfaction, psychological well-being and work stress are rarely assessed. According to the perceived organisational support theory, workers' productivity is influenced by the extent that workers believe their organisation values their work contributions and well-being. The current review aims to examine training interventions that also include organisational components of support for workers. To date, no evaluation on the strength of the effects of the rigorously tested studies has been conducted, in particular focusing on both worker and organisational outcomes.

Job satisfaction has a well-established negative correlation with high job demands and stress. A meta-analysis of 31 studies of nurses found job dissatisfaction was most strongly correlated with job stress (Zangaro & Soeken,

2007). Further, job stress is considered a major factor for work-related injuries, workplace turnovers, absenteeism, and workers compensation claims at an international level (Richardson & Martin, 2004). The risk of developing a psychological disorder, such as depression, is higher for workers with high work demands, reduced autonomy (i.e., low decisional power and the lack of control over work), strain, overload and pressure (Darr & Johns, 2008).

At the basic level, capacity refers to the amount that something or someone can produce as well as receive or hold (Moore, 2004). In terms of organisational systems, capacity therefore relates to an organisation's ability to provide or hold and maintain services, workers' skill and aptitude to absorb knowledge, fulfil roles, meet demands and standards, all resulting in a desired consumer outcome, such as quality care or satisfaction. Capacity in health and community care will need to grow to maintain and adapt service provision in light of future demands. A systematic review of the efficacy of training interventions for dementia care workers will help provide some direction for services in the future wishing to improve the capacity of their workforce. In turn, a focus on outcomes for workers and organisations will show which interventions produce the best effects in different stakeholders.

A focus on studies that provide information for multiple domains will allow the analysis to adopt a holistic approach, whereby multiple factors proven to build the capacity of dementia care service providers can be examined. Thus, Study 1 will extend the understanding of capacity building, beyond a dementia training focus on workforce knowledge and skill. Including studies that evaluate worker mood and well-being will also allow some potential barriers of learning and translation to be explored. Further, to have some sense of whether the

intervention is impacting more broadly on workforce capacity there has to be markers of worker capacity such as job stress, retention and absenteeism.

This study reviews systematically all studies published in the past 21 years testing the effectiveness of dementia training interventions for health care workers. The review details the reasons for study selection based on inclusion and exclusion criteria, which are detailed in the methods section. Results are presented by displaying the interventions' training format, setting and outcomes for interventions. Methodological concerns related to the included studies are also presented. Finally, implications and recommendations are made for capacity building in dementia care.

Method

The literature search sought to capture all studies from 1990-2011 that evaluated training for paid health workers who care for people with dementia. This period was selected to capture developments of the last 21 years of research, with particular interest in randomised control study designs in the field. Relevant publications were identified searching computerised databases; Web of Science, PsycINFO, Scopus, ProQuest, and PubMed for terms such as “dementia training”, “dementia care training”, “dementia training intervention”, “dementia staff training” and “dementia education”. Multiple search strategies were used to maximise the probability of locating as many relevant articles as possible. Finally, the references from papers located through these database searches were also examined for additional relevant papers. Thus, two recent review papers proved useful for identifying dementia specific studies that met the selection criteria. One critiqued interventions to train staff to manage the mental well-being of elderly residential care patients, (Moyle, Hsu, Lieff, & Vernooij-Dassen, 2010). The

second examined professional development for medical and other health professionals working in generic health settings (Rampatige, Dunt, Doyle, Day, & van Dort, 2009).

To inform knowledge about interactive processes between worker and organisational functioning, this review focuses only on interventions that involved dual outcome domains. That is, included studies needed to have assessed both worker (e.g., dementia knowledge, job satisfaction and well-being) and organisational outcomes (such as retention and service delivery). Studies that do not assess both outcome domains are limited in their potential to inform practice and policy for enhancing the dementia workforce in a sustained way. For example, though a worker training intervention might have positive effects on worker outcomes in the relative short term, in the absence of knowledge about organisational outcomes, the impact of worker training on organisational health and core business (Jensen, 2011) is unknown. Conversely, if an organisational intervention does not assess worker outcomes the results can not inform whether any organisational change has translated to, or affected, worker capacity or well-being.

Thus, only articles meeting the following inclusion criteria were chosen for further analysis: the study must;

- involve an intervention that targets workers who provided support or care to people with dementia and or their informal carers (this could include workers employed in residential facilities or community based services),
- assess some aspect of worker capacity or well-being (e.g., job stress, knowledge, mood) as well as organisational factors (e.g., service delivery or retention),

- adopt a randomised controlled design (RCT) and evaluate the effects of the intervention using empirical data,
- be published in English,
- be published between 1990 and 2011.

Studies were excluded from the review if no worker or organisational assessment was undertaken by the authors, and if the study predominantly focused on outcomes for the person with dementia or their informal carer. Studies that focused primarily on behaviour change in people with dementia via training staff in specific behaviour changes skills were excluded if they did not include worker related outcomes (Allen-Burge, Stevens, & Burgio, 1999; McCabe, Davison, & George, 2007). Whilst these may provide workers with confidence in a specific domain of dementia care, the focus of these interventions is not on workers well-being per se. Papers were also excluded if they were not dementia specific (i.e., a study testing a training intervention of a generalised educational resource for nurses in elderly care). Studies that only assessed change on one domain were also excluded. Two of the authors reviewed the identified papers for consistency of selection and if discrepancy occurred this was discussed in light of the eligibility criteria until consensus was reached. The papers were summarised and categorised as a means of identifying the applicability of training to the workplace, and review best effects for service providers considering organisational training and evaluation in dementia.

Where possible, effect sizes (Cohen's *d*) were calculated to determine the strength of effect of the interventions on measured outcomes and produce comparison across domains. The format, duration, and content of the interventions, and therapist variables, such as the qualifications and training of the

intervention facilitators are also reported in the review. These variables inform researchers about the potential to replicate, disseminate, and sustain successful interventions in other organisational settings or workforces, or can help explain null effects. In addition, the methodological quality for each study was calculated based on a rating scale developed from criteria based on the Consolidated Standards of Reporting Trials (CONSORT; Moher, Schulz, & Altman, 2001) and by Brodaty et al. (2003), which was in part also adopted by a previous systematic review of nursing home staff training in dementia care (Kuske et al., 2007). Methodological comments are discussed in reference to the size of effects across outcome domains.

Results

The search strategy identified 74 studies after review of initial abstracts were made for dementia training programs. Of these, 68 studies did not meet inclusion criteria (with 46 of these excluded as they were not RCT designs). In total 22 RCT studies were excluded from the current review. Nine RCT studies were excluded as they did not assess worker outcomes (Callahan et al., 2006; Downs et al., 2006; Fossey et al., 2006; Moniz-Cook et al., 2008; Proctor et al., 1999; Rovner, Steele, Shmuely, & Folstein, 1996; Teri, McCurry, Logsdon, & Gibbons, 2005; Testad, Ballard, Bronnick, & Aarsland, 2010; Vickrey et al., 2006). Seven RCT studies were excluded as they did not assess organisational outcomes (Burgio et al., 2001; Burgio et al., 2002; Chodosh et al., 2007; Davison et al., 2007; Teri, Huda, Gibbons, Young, & Van Leynseele, 2005; Visser et al., 2008; Wells, Dawson, Sidani, Craig, & Pringle, 2000). Chodosh et al. (2007) did assess quality of care delivered, however this was measured from the primary care physician's perspective and therefore not a true organisational outcome. One

intervention tested by Smeyer et al. (1992) was not focused on dementia, but instead general training in nursing home care and was therefore excluded, despite assessing changes in job roles. Three RCT studies did not report any results and only described the intervention under examination (Holle et al., 2009; Perry et al., 2008; Vollmar, Butzlaff, Lefering, & Rieger, 2007). A further two RCT studies were excluded as they only offered simulated results (i.e., neurologists reviewing dementia case scenarios in a lab based study replicating dementia symptoms in actors; Holloway, Gifford, Frankel, & Vickrey, 1999; Schindel-Martin et al., 2003).

A total of six RCT studies were included in the review (see Table 7 for studies presented in rank order based on methodological rigor determined by concerns raised in Table 8). Five studies took place in the United States and one in Finland. Training interventions that targeted change for health care workers, the organisation and or consumers fell into two categories; interventions i) with staff support component ii) without staff support component. All studies included in the review took place in the residential care setting. Despite the eligibility criteria of the review including the community setting no studies were found for the community setting that assessed both worker and organisational outcomes.

The review describes training outcomes for 2274 workers in dementia care. Workers' range from nursing assistants and personal carers with practice certificates in formal care-giving to registered nurses with bachelor degrees. Organisational settings include residential care facilities and specific dementia units and hospital wards. Of those studies evaluating effects for consumers, 639 people with dementia and their family or carers were reported. Half the training interventions provided an additional staff support component. Results of the

current review show over the past 21 years, ways to improve the capacity of health care workers in the dementia setting has focused on improving knowledge in dementia via education, skills and education training in behaviour management and in some cases organisational support in the form of supervision.

Table 7

Summary of RCT Studies Testing Training Interventions in Dementia Care

Outcomes [Effect Size = Cohen's d]														
Study	Participants		Training Intervention			Worker		Organisational		Consumer				
	[Quality Rating]	N Worker (N Patient ± Carer)	N Conditions (Follow-up Months)	Components (Indiv/Group)	Frequency, Length (Duration)	Knowledge	Comm	Burnout/ Work Stress	Mood	Sat	Retention	Service Delivery/ Other	PWD	Carer
Origin		[% Refusal]												
Training interventions with staff support component														
Finnema et al. (2005)	99	1 INT	CM + Network	2 x 4 hrs –			0	x			0		x	
[20.5]	Res Care	1 C	± Couns ±	10 x 8 hrs										
NL	Nurse	(post)	ClinsV ±	(2 days –										
	(146)		Mentor	9 months)										
	[ns]		(group ± indiv)											

Outcomes [Effect Size = Cohen's d]														
Study	Participants		Training Intervention			Worker							Organisational	Consumer
	[Quality Rating]	N Worker (N Patient ± Carer)	N Conditions (Follow-Up Months)	Components (Indiv/Group)	Frequency, Length (Duration)	Knowledge	Comm	Burnout/ Work Stress	Mood	Sat	Retention	Service Delivery/ Other		
Origin														
Pillemer et al. (2008)		762	1 INT	D Ed + Nurse Advocate	3 x 7 hrs (3 days)			0		0		+	x	
[12.5]		Res Care Nurse	1 C (12)	tailored to site (group)										
US		(0) [ns]												
McCallion, Toseland, Lacey and Banks (1999)		88	1 INT	D Ed + Comm + SV	5 x 45 mins (group) +	x						#	x	x
[11]		Res Care Nurse	1 WLC (6)	(indiv + group)	4 x 30 mins (indiv) (ns)	[0.4]							[0.2-0.3]	[0.3-0.5]
US		(105) [ns]												

Outcomes [Effect Size = Cohen's d]																
Study	Participants		Training Intervention		Worker								Organisational		Consumer	
	[Quality Rating]	N Worker (N Patient ± Carer)	N Conditions (Follow-up Months)	Components (Indiv/Group)	Frequency, Length (Duration)	Knowledge	Comm	Burnout/ Work Stress	Mood	Sat	Retention	Service Delivery/ Other	PWD	Carer		
Origin		[% Refusal]														
Training interventions without staff support component																
Robison et al. (2007)	384	Res Care	1 INT	D Ed + Comm & Conflict Res	1 x 4-5 hrs +		x	+	0			+	+	+		
[13]		Nurse	1 C (6)	(group)	1 x 2 hrs (1 day)											
US		(388)														
		[13]														
Zimmerman et al. (2010)	662	Res Care	1 INT	Comm + Pain Ed ±	4-6 x 1 hr (6 weeks)		x	+	x	0		x				
[11]		Nurse	1C (3)	Leadership Ed												
US		(0)	(post)	(group)												
		[12]														

Study	Participants		Training Intervention		Outcomes [Effect Size = Cohen's d]								
					Worker		Organisational			Consumer			
[Quality Rating]	N Worker (N Patient ± Carer)	N Conditions (Follow-up Months)	Components (Indiv/Group)	Frequency, Length (Duration)	Knowledge	Comm	Burnout/ Work Stress	Mood	Sat	Retention	Service Delivery/ Other	PWD	Carer
Origin	[% Refusal]												
Rosen et al. (2002)	279 Res Care	2 INT 1 C (6)	D Ed + BM ± Computer Resource (group or indiv)	6 x 50 mins (6 months)					+	0			
[9] US	Nurse (ns) [21]												

Note. % worker refusal; PWD = people with dementia.
Setting: Res Care = residential care; Design: C = control; INT= intervention; WLC = wait list control.
Format: group/ indiv = intervention delivered in a group or one-on-one.
Intervention components: BM = behavioural management; CM = case management; ClinsV= clinical supervision; Comm = communication; Conflict Res = conflict resolution; Couns = counselling; D = dementia; Ed = educational / instructional; Network = network meetings; Nurse Advocate = a nurse who advocates for workers needs; Mentor = a peer mentor or staff member who guides/ monitors workers; Pain = pain management; SV = supervision for workers to practice skills and have feedback. Outcomes: Comm = communication; Sat = satisfaction; + = significant improvement monitored to follow up; x = significant improvement, but not to follow up; # = no improvement at time one, significant improvement found at follow up; 0 = no effect.

Table 8

Rating of RCT Studies Descending in Research Quality

CRITERIA FOR RATING QUALITY OF STUDIES									
STUDY	INTRO	INTERV	RANDOM	SUBJECTS	OUTCOMES	STATISTICS	RESULTS	DISCUSSION	Total Score
	Theory driven Specific hypotheses	Evidence-based Precise content Control/waitlist content reported Delivery method and timing Adherence	Report method Allocation concealment Describe implementation	Eligibility criteria Masking/blinding Participant flow Recruitment length	Valid & reliable Identify primary and secondary Objective/ corroborative measure (s)	Sufficient power Baseline equivalence Compare groups Adjust multiple comparisons Intention-to-treat	Blinding Follow-up ≥ 6 months Effect sizes & confidence intervals	Interpretation balanced Acknowledge limitations	
Maximum score	2	5	3	4	3	5	3	2	27
Finnema et al. (2005)	2	3.5	0	3.5	3	4.5	2	2	20.5
Robison et al. (2007)	1	2	1	2	2	2	1	2	13

CRITERIA FOR RATING QUALITY OF STUDIES									
STUDY	INTRO	INTERV	RANDOM	SUBJECTS	OUTCOMES	STATISTICS	RESULTS	DISCUSSION	Total Score
	Theory driven Specific hypotheses	Evidence-based Precise content Control/waitlist content reported Delivery method and timing Adherence	Report method Allocation concealment Describe implementation	Eligibility criteria Masking/blinding Participant flow Recruitment length	Valid & reliable Identify primary and secondary Objective/corroborative measure (s)	Sufficient power Baseline equivalence Compare groups Adjust multiple comparisons Intention-to-treat	Blinding Follow-up ≥ 6 months Effect sizes & confidence intervals	Interpretation balanced Acknowledge limitations	
Pillemer et al. (2008)	1	2	1	2	1.5	3	1	1	12.5
McCallion et al. (1999)	1	1	0	1	2.5	1	2.5	2	11
Zimmerman et al. (2010)	1	2	0	2.5	1	2.5	0	2	11

CRITERIA FOR RATING QUALITY OF STUDIES

STUDY	INTRO	INTERV	RANDOM	SUBJECTS	OUTCOMES	STATISTICS	RESULTS	DISCUSSION	Total Score
	Theory driven Specific hypotheses	Evidence-based Precise content Control/waitlist content reported Delivery method and timing Adherence	Report method Allocation concealment Describe implementation	Eligibility criteria Masking/blinding Participant flow Recruitment length	Valid & reliable Identify primary and secondary Objective/corroborative measure (s)	Sufficient power Baseline equivalence Compare groups Adjust multiple comparisons Intention-to-treat	Blinding Follow-up ≥ 6 months Effect sizes & confidence intervals	Interpretation balanced Acknowledge limitations	
Rosen et al. (2002)	0	3	0	0	0.5	3	1	1.5	9

Note. INTRO = Introduction; RANDOM = Randomisation; Some studies could attract 0.5 of a mark if there was reference to a given criteria, but incomplete information, examples of this include; Criteria = Intervention Adherence - intervention and control groups were supervised by different nursing advisors, but no details were reported on whether the intended topics were delivered, Criteria = Statistics Sufficient Power - reports that power was sufficient, but calculations not provided.

Training format and setting

The majority of training interventions for health workers in dementia care included in the review followed a group format, with three interventions also adopting the use of individual format. There was only one study selected in the review where workers were randomly allocated to receive training individually. Training interventions aimed to improve capacity in dementia health care by adopting the use of multiple component programs. In total 14 types of components were used in the six interventions, displayed in Table 7. The most commonly adopted training component was dementia education or instructional training. Information about dementia was generally delivered through mixed methods adopting the use of lectures, video, role-play, group exercises and case discussions. The average length of training interventions was a total of approximately 22 hours. All trainings lasted under 21 hours, except for one, lasting a total of 88 hours. Training facilitators had health professional qualifications such as nurse, social worker or physician backgrounds. All studies reported expert knowledge in dementia held by facilitators, in the form of advanced degrees, or specialist training.

Outcomes for interventions with staff support

Interventions that adopt a staff support component involve some type of interaction between staff in both nurse assistant and more senior roles. Staff support was delivered in the form of supervision both of a general and clinical nature and a mentor or nurse advocate.

Worker outcomes are varied. Two out of three interventions produced positive, but not lasting outcomes for workers. Nurse assistants' who reported using more counselling (emotion-oriented) skills showed improvements in

general stress levels (Finnema et al., 2005). However this medium level effect was not sustained over time. No effects were found for work stress or burnout (despite some improvements in general stress) or competence and job satisfaction.

Knowledge in treatment care and behavioural management improved for nurse assistants after participating in an intervention with instructional training on dementia and communication (McCallion et al., 1999). This effect was medium in size and it did not last over time. The intervention tested by McCallion et al. (1999) did not produce improvements in dementia knowledge, despite one of the core components targeting this area.

Mixed results were found for organisational outcomes. Lasting effects were found for retention and retention efforts within the organisation when nurses undertook instructional training on dementia and a nurse advocate was positioned in the workplace (Pillemer et al., 2008), however no calculations of size of effect could be made. Delayed improvements were found for retention when nurse assistants attended instructional training on dementia communication and received supervision (McCallion et al., 1999). Again the effect size could not be calculated. Despite two studies reporting positive results for retention, Finnema et al. (2005) found no improvements in staff absenteeism at a nursing home. Non-lasting effects were found for service delivery in the form of care quality, staff education quality (no effect sizes) and the use of physical and chemical restraints (small effects sizes).

Some non-lasting effects were found for consumers, with the largest effect for self-care (Cohen's $d = 0.6$) of people with dementia in a nursing home. The same intervention tested by Finnema et al. (2005) found a non-lasting medium effect for emotional balance of residents with dementia, but this was only for

residents who were in less need of assistance, with mild-moderate levels of dementia. Depression and aggressive behaviours (Cohen's $d = 0.2$) improved in people with dementia after staff training in dementia education communication and supervision (McCallion et al., 1999). Despite these small to medium effects, none were found for behavioural problems for people with dementia. No outcomes were reported for carers of people with dementia in the studies that tested interventions with a staff support component.

Outcomes for interventions without staff support

Two interventions without staff support found lasting effects (Robison et al., 2007; Rosen et al., 2002). All interventions adopted a group educational component to deliver dementia education, in association with other components such as communication or behavioural management strategies. No effect sizes could be calculated for the intervention outcomes for any study in this category.

Worker outcomes showed improvements for knowledge in general (lasting over time; Rosen et al., 2002) and also specific knowledge in pain (not maintained to follow-up; Zimmerman et al., 2010). Satisfaction with training and compliance to attend training were found to be higher for nurses who completed training in using a computer resource about dementia and behavioural management than nurses who attended traditional group training in lecture format (Rosen et al., 2002). Lasting effects were found for general communication when care workers and their supervisors undertook instructional education on communication, pain and leadership (Zimmerman et al., 2010). When instructional education focused on dementia, communication and conflict resolution, non-lasting effects for nurse communication with family members and carers of people with dementia were found (Robison et al., 2007). Improvements were lasting for worker ratings of

burnout (Robison et al., 2007), but work stress worsened, however was not lasting (Zimmerman et al., 2010). No effects were found for mood (Robison et al., 2007) or satisfaction of care workers and supervisors with care provision for people with dementia (Zimmerman et al., 2010).

The number of programs offered to families increased after nurses attended training in dementia, communication and conflict resolution and remained to follow-up (Robison et al., 2007). Care workers and supervisors reported improvements in supervisor support and work with other staff after group education in communication, pain and leadership (Zimmerman et al., 2010), however these were not lasting effects. No effects were found on retention (Rosen et al., 2002). Consumer outcomes were found by Robison et al. (2007) with people with dementia improving behaviourally and family members and or carers improving on communication with staff and their level of involvement at the nursing home.

Methodological concerns

All studies had some level of methodological problem (see Table 8) and were ranked in order of highest to lowest quality rating. The study by Finnema et al. (2005) scored the highest quality rating of the six RCTs in the review, but methodological problems were evident. Concerns were found in the lack of reporting about randomisation methods, such as allocation concealment and implementation. Only partial training adherence steps were taken. Intervention and control groups were supervised by different nursing advisors. In addition nurse participants were assessed by family members on their interaction with people with dementia, however this attempt to monitor compliance related more to an outcome of the training than to whether trainers delivered the appropriate

material consistently. No reports were made regarding researchers blinding of treatment group during analysis of results. Despite scoring the highest quality rating of the six studies, Finnema et al. (2005) found no lasting effects of the dementia training intervention on worker, organisational or consumer outcomes.

The study by Robison et al. (2007) had the second highest quality rating, scoring 13 out of 26 points. In spite of ranking second, the rationale of the study was not theory driven and no content was reported for the control condition even though precise content existed for the intervention via the form of a training manual. While there was a training manual, no information about adherence to the training manual was reported. Stratification was reported as the method for randomisation, but no details were provided for allocation concealment and implementation methods, such as who generated the allocation sequence and enrolled participants. Length of recruitment and subject masking was unclear, so too were primary and secondary outcomes. Baseline differences were found for people with dementia and the length of their stay at the residential facility and for workers on interpersonal conflict, affecting the ability to say that the effects were due solely to the intervention and were not pre-existing. No adjustments were made for multiple analyses, no effect sizes were reported and although research staff completed most of the data collection, no reports were made of blinding researchers to treatment.

The third highest rating study in the review scored 12.5 and tested the effects of dementia education and nurse advocacy tailored to each nursing home site. Pillemer et al. (2008) had eight similar reasons for methodological concern to Robison et al. (2007). These included no mention of a specific theory in the introduction of the study, no details of the content of the control group, allocation

concealment or implementation methods, no mention of blinding of those delivering the intervention or outcome assessors, unclear recruitment length and no calculation of effect sizes. Pillemer et al. (2008) did not consider power analysis and failed to acknowledge the limitation in intervention design, as there was variation in nurse advocate roles across facility, potentially reducing the validity of comparison.

The study by McCallion et al. (1999) was given a quality rating of 11 out of 26. The study was developed to resolve existing problems in communication with people with dementia in nursing homes, but the rationale was not theory driven and neither the intervention evidence-based. A waitlist control was adopted; no reason for point deduction alone, but cause for concern was the content of the control remained unreported. Another confounding influence was the waitlist control continued to receive usual in-service training (no details on type of training were provided). Concerns were evident for randomization methods as no reports were made about allocation, implementation or masking of participants. The flow of participants was a challenge to understand as drop outs and refusals were not reported. Despite the sound psychometrics of the overall measures, the main outcome finding was reliant upon the subscale of a measure, a process that increases the likelihood of type one errors. Statistical adjustments were not made for multiple comparisons and no intention to treat analysis was completed.

Eleven was the total quality rating for the study by Zimmerman et al. (2010). The rationale for testing the intervention was theory based, but only general hypotheses were considered in the introduction of the study. Poor description of the processes of randomisation was evident with outcome measures

experimenter derived or modified. Qualitative assessment failed to consider inter-rater agreement on coding methods, providing subjective analysis open to individual coder bias. Low power was reported and methodological problems were evident in the results with no blinding of researchers. Only one outcome was assessed at three time points, while others were only assessed at pre-post time points, with the follow-up time less than six months.

The study by Rosen et al. (2002) was rated nine for quality. A novel computer-based approach was adopted by Rosen et al. (2002) to deliver training to nursing home staff in mental health and dementia, but the rationale for the study was not based in theory and no specific hypotheses were described. The intervention content derived from focus groups of facility educators identifying topics for training. Similar to other low rated studies, poor randomisation and treatment of subject methods were evident. Concerns were apparent about the reliability and validity of the outcomes as all measures were experimenter derived. Again baseline differences were a problem, ensuring caution when interpreting results.

Discussion

Over the past 21 years only six RCT interventions have been conducted that target capacity building in dementia care, including outcomes for both the worker and organisation, as identified by the selection criteria in the current review. No studies were identified in the review for the community setting. Of the six interventions tested, all were multi-component, most frequently containing dementia education instructional modules. Outcomes were varied across workers, the organisation and consumers. All studies included in the review had underlying methodological problems.

Limitations of the current review should be acknowledged as these can influence the interpretation of the results. There was a bias towards published studies. Unpublished papers tend to report null results. Significant and positive results are published more often leading to a subsequent over representation of positive results, not uncommon in systematic reviews (Higgins & Green, 2011). The review adopted a very focused approach, exclusively on studies that assessed both worker and organisational variables. It was determined that these studies have the greatest potential to inform how these two domains might operate in concert to improve workforce capacity and preparedness. Excluding studies that focused only on worker outcomes may have limited findings about interventions that are efficacious for improving a specific set of worker skills or knowledge in a given workplace. However, these studies do not inform knowledge about the organisational variables that might be essential for broader dissemination of interventions, beyond specific workplaces and settings. Similarly, while studies that only assess organisational outcomes might inform aspects of organisational change per se, the findings do not shed light on workers' responses and

satisfaction with these interventions, hence the feasibility and viability of these interventions for building workforce capacity is unknown.

Mixed results were found across interventions, with no consistent finding for outcome domains. No patterns were evident for interventions with or without staff support. However, organisational psychology theory can offer a rationale for inclusion of staff support in such interventions. The job demand-resources (JD-R) model purports that burnout is the product of job demands exceeding job resources (Demerouti et al., 2001). Therefore, when job resources (such as ongoing supervision, a staff mentor, or educational resources) are present in a service, these resources can act to protect worker health and uphold work performance in the face of high demands. Providing conjunctive organisational support to workers may assist in capacity building.

There have been numerous studies particularly in the field of nursing that target training to help staff manage a given patient outcome. Few have focused on the workers well-being or ways to enhance role functioning and resilience or measured these capacity building outcomes. In the current review only three studies conducted some form of assessment on worker well-being (mood, stress or burnout). Three studies found non-lasting effects (Finnema et al., 2005; Robison et al., 2007; Zimmerman et al., 2010), and one found lasting effects on rates of burnout (Robison et al., 2007). Of all these findings only one outcome reported an effect size (Finnema et al., 2005; medium non-lasting improvements in general stress). This mix and inconsistency of results may have occurred as the interventions in the review did not directly target worker well-being.

Care workers and nurses in dementia care perform instrumental tasks, such as bathing and dressing. Wellin (2008) recognises the interpersonal and emotional

relations in which such tasks are embedded. No interventions in the review targeted aspects of the emotional regulation of workers and how they manage the intimacies of caring, particularly concerns of privacy and dignity. Other than communication, the relationship aspects of the care role, such as closeness and personal boundary issues are ignored in training modules of rigorously tested interventions. Training of care workers is usually provided by their employing organisation and often focuses on basic nutrition, infection control, and manual handling techniques, not topics on resident rights, ethical concerns, dementia care, family stress issues, communication, and spirituality (Wellin, 2008).

Commitment to the consumer is one of the highest motivating factors of care worker participation in the workforce (Howes et al., 2008). Job dissatisfaction at not being able to deliver quality care is one of the main reasons workers quit the dementia care industry (Vernooji-Dassen et al., 2009). Barriers to improving capacity of the dementia care workforce may relate to factors that interfere with workers' commitment to clients and workers' appraisals of providing quality care. Challenges for care workers is lack of time to complete their job effectively (Booth et al., 2005) and attend training when arranging coverage of shifts is affected by both an attachment to clients and concerns for other workers' unfamiliarity with client's needs (Elliott, Stirling, Martin, Robinson, & Scott, 2012 in pres). Determining how care workers can remain feeling committed to clients by providing quality care, while undergoing training or job development is paramount to engaging workers in capacity building activities.

It appears that emotional regulation, stress management and psychological well-being of dementia workers is not incorporated into the capacity picture, which is peculiar considering the well established links between work

performance and mental health. Job stress and burnout have implication for retaining workers in employment, as well as affecting their ability to participate in work roles. Several meta-analytic reviews conducted over five decades have established the relationship between general health, psychological well-being, work stress and dissatisfaction (Bonde, 2008; Darr & Johns, 2008; Standsfeld & Candy, 2006). Future studies addressing capacity building in the dementia care workforce need take into account workers' health and well-being and how job tasks and delivering services to people with high care needs impacts on their ability to receive intervention and deliver quality care.

The studies in the review provided little information about the skill level of workers and their stage of career which may account for difference between intervention outcomes. Some studies tried to correct such problems by adopting the use of a training manual, however little attempt was made to review adherence to the intervention and training guidelines. There was little detail about intervention design and implementation in studies included in the review, a finding supported by Nielsen et al. (2010) who recommend future studies provide in-depth information in these areas. Multiple concerns were raised in the current review regarding the methodological quality of the studies, with five of the studies rating low on study quality. The current review confirms previous findings of methodological weakness (Kuske et al., 2007) in studies testing the effects of training interventions in dementia care.

Evidence-based science has exposed a significant gap in community dementia care. The current review reports that no capacity building intervention for training in dementia care has been rigorously tested following an RCT design. This finding is a call for action to politicians and umbrella groups worldwide to

fund and set up more rigorous research into the community arena of dementia care. Internationally, community aged care is already experiencing considerable strain and is one of the fastest growing occupational sectors. Without significant activity at both the coal face and research end, the existing problems of turnover, recruitment, retention, regulation and training issues, to mention a few, will become much worse.

From this review it is recommended that future studies focus on two related agendas. The first focus is on intervention effectiveness, with RCT designs recognised as the gold standard. Clustered RCTs may be useful to overcome some barriers associated with randomisation in workforce studies such as masking, as well as fidelity concerns. However, an important second agenda to pursue is to understand more about intervention mechanisms and or mediators of intervention response to refine future development. In this regard problems with defining and testing intervention components and the best areas to target for enhancing adjustment could be overcome by using a mixed methods design. Such studies have the potential to increase our knowledge on the best ways to build capacity and resilience in the dementia care workforce. Future research that addresses these concerns will improve our ability to support the dementia workforce. The findings from this review guide an agenda to overcome methodological obstacles in dementia care training.

The next chapter will present the first of two related studies that follow the recommendations of the current review, reported in this chapter. Chapter Five will present Study 2 – Part A, which is an in-depth qualitative review of dementia care workers' perceptions of key vocational domains, with a focus on the care role. Study 2 – Part B highlights profiles of psychological adjustment that identify

factors that relate to resiliency and distress in dementia care workers (and will be reported in Chapter Six). This approach uses mixed data, both qualitative and quantitative, to identify the best areas to target for enhancing employee adjustment. Subsequently, the findings will inform organisations and policy makers about the development of intervention components that aim to build the capacity of the dementia care workforce.

Chapter 5

The Power of Occupational Communion for the Dementia Care Workforce

(Study 2 - Part A)

“...being invited into people’s homes, and sort of talking to people, ... I know that if I share a cup of tea with them, ... they’re going to sort of open up and talk and I find that’s probably the best part of the work”.

A worker’s comment about client related occupational communion as the best part of her job.

“The worst part of work is not enough interaction with other [formal] carers, it’s something that we really have to organise ourselves... to be able to share the ups and downs of life and also debrief. Talk about tricks of the trade. That would be really very useful”.

A worker’s comments about colleague related occupational communion as an unmet need in her job.

Dementia has been declared an international public health priority by the WHO and ADI (2012) and it will be a leading cause of disability burden in the 21st century. The number of people with dementia around the globe is estimated to grow to over 115.4 million by 2050, which is three times the current prevalence (Wimo & Prince, 2010). Despite the fact that the paid care workforce is one of the largest and fastest growing workforces worldwide (Hecker, 2005), in Australia alone, there will need to be approximately 827,100 aged care workers by 2050 (up from 304,000 in 2010) to meet the demand generated by population ageing (DoHA, 2012). Whereas, United States estimates indicate that 1.3 million new community-based care workers (e.g., personal care assistants and home health aides) will be added to this occupational sector over the first two decades of the 21st century (USBLS, 2012). Barriers to high quality dementia care are linked to workforce issues and include workers' limited knowledge about the disease, with low numbers of staff receiving dementia care training, even amongst those working in specialist dementia services (APPG, 2009). A well trained, qualified and appropriately skilled workforce is needed to provide quality care to people with dementia.

As previously stated in Australia, care workers operate within a three-tiered system including aged care nursing homes, hostels and support programs for people living in the community (community care; Henderson & Caplan, 2008). They provide the practical care and personal assistance not only to people with dementia, but also the general elderly population, or those living with disabilities. The majority (91%) of care workers based in the community are female and 50 years of age (Martin & King, 2008). Very low numbers of care workers enjoy full-time permanency at their workplace, and it is most likely that they are employed

under permanent part-time contracts (Richardson & Martin, 2004). Other nations, such as the United Kingdom and the United States share similar care workforce characteristics including low levels of education, qualifications and remuneration (Figueriredo, 2011; Hussein & Manthorpe, 2011).

Community dementia care is growing due to a combination of patient choice to remain in their home and the relative savings in costs compared with residential care (Henderson & Caplan, 2008). In the United States, home and community-based jobs dominate direct care employment, with the majority of care workers employed in home and community-based settings, and not in institutional settings (i.e., nursing care facilities; PHI, 2011). Further, it is predicted within the next six years that home and community-based care workers in the United States will outnumber facility workers nearly two to one (PHI, 2011). The majority of research set in Australian community care is qualitative and government documents provide statistical analysis and policy direction (Henderson & Caplan, 2008). A recent systematic review of resilience and capacity building in dementia care found there is a lack of rigorous research set in the community workforce sphere (Elliott et al., 2012). Thus, community-based capacity building research that informs workforce development is an area in need of further investigation.

Dementia care workers perform instrumental tasks, such as bathing and dressing clients, which are embedded in interpersonal and emotional relations (Wellin, 2008). A systematic review of rigorously tested dementia training interventions that focused on worker and organisational outcomes, found no training components adequately addressed aspects of the emotional regulation of workers (Elliott et al., 2012). In particular, there was a lack of training components that focused on how workers' managed the intimacies of caring such

as concerns of privacy and dignity of people with dementia (Elliott et al., 2012). This is surprising considering the community care role is not only based in interpersonal interactions but also in the social context where workers' deliver support in the personal domain of the care recipient's home. Therefore, in the current chapter, a focus on workers' perceptions of their relationships with care recipients is explored, to illustrate the social and interpersonal aspects of the paid community care role.

Human resource factors such as such as job stress and high job demands, as well as turnover have been widely investigated in health services and aged care research. Job stress and high job demands have been found to be associated with poor psychological well-being and workers' compensation claims at an international level (Richardson & Rothstein, 2008). In Australia, a quarter of care workers, and one in five nurses have to be replaced each year by their current employer (Martin & King, 2008). Turnover was considered a "serious" or "very serious" direct care workforce issue by 97% of American States in 2007, a substantial increase from 76% in 2005 (PHI, 2009). In addition, the direct cost of turnover in long-term care in the United States is at least US \$2,500 per worker (based on a conservative working estimate; Seavey, 2004). Workers who leave the direct care workforce experience a lack of respect and inadequate management, and those who stay appear to have a strong commitment to their clients (Mittal et al., 2009). Finding ways to build the capacity of the existing workforce, while improving employee recruitment and retention rates in dementia care, are paramount concerns if organisations are to be prepared for the predicted changes in the public health landscape.

Theoretical perspectives

Bandura's (1988) theory of social psychology explains human behaviour through social interaction and he proposed this theory has an organisational application as it "provides explicit guidelines on how to equip people with competencies, self-regulatory capabilities and a resilient sense of efficacy that enables them to enhance their psychological well-being and personal accomplishment" (p. 299). Social psychology theory may apply to the dementia care workforce, due to the inherent social nature of job tasks and duties in the care role. A sense of *communion* (coined by Bakan, 1966) may form part of the characteristics of this workforce, as it refers to a person's desire to relate to, collaborate and unite with others, where individual fulfillment is experienced through relationships and a sense of belonging (Guisinger & Blatt, 1994; McAdams, 1993).

There is no debate that the direct care workforce is highly committed to the people they care for (Howes et al., 2008), although what underlies this strong commitment remains relatively unknown. While research about agency and communion has occurred in the business context, such as the relationship of these variables to corporations' social responsibility (Van Marrewijk, 2003) and for their importance for women in their careers generally (Ellery-Brown, 2011), little has focused on the application of communion to the paid caring role. It is hypothesised that the interconnectedness of care workers to their clients' lives through assistance with everyday tasks may be at the core of commitment to work and other adaptive employee functions. The implications of communion in this workforce are explored in relation to education and training, attraction to work and organisational commitment.

Key factors within the organisational psychology literature are relevant for employee well-being and performance. Namely, job demands and job resources (JD-R; Dermerouti et al., 2001) where a balance between the two has been shown to influence workers' experience of job stress. When job demands outweigh job resources workers show burnout and disengagement from work. Most research on JD-R has applied to clerical employees and some general health workers. Congruence between worker and organisational values have also been found to be relevant for attraction to work, as well as commitment and engagement at work, known as the person-organisation fit theory (P-O fit; Kristof, 1996). To date, the theory of P-O fit has not been applied to the dementia care workforce and thus will be investigated within the current study presented in this chapter.

While the construct of P-O fit has not been applied to the dementia care workforce it has been applied to staff outcomes in services for people with disabilities (Hatton et al., 1999). Employees in the disability setting reported that an ideal organisational culture included high staff rewards, tolerance and orientation towards staff, and fostering social relationships with colleagues, as well as low demands (Hatton et al., 1999). While the study by Hatton et al. (1999) included all employees in the organisations delivering support services (such as managerial, administration, frontline and cleaning staff), the findings may still apply for workers in dementia care. The disabilities and aged care sectors in Australia often cross over in responsibilities (i.e., HACC) and the supportive care tasks of frontline workers share similarities.

Within the social and organisational psychology literature there is little focus on how such theories can be applied to aged and dementia care workforces, particularly the nature of the relationship between the two perspectives. Thus,

exploring the relationship between social and organisational psychology may offer insights into the development of capacity building interventions for the community-based dementia care workforce. By focusing on the community-based workforce, the current research aims to fill an identified gap (Elliott et al., 2012) in this care setting. Thus, community-based capacity building research that informs workforce development and preparedness to cope with future demands is an area in need of further investigation.

Exploring workers' unique perspectives will allow for representation of an array of ideas and thoughts on community dementia care, a setting that will experience exponential growth over the next several decades. A bottom-up approach to investigating community dementia care provides a narrative to the frontline view of current workplace practices and challenges in the area. Applying social and organisational psychology theories will provide an in-depth focus on dementia care workers. Further, a review of the potential capacity building domains in community dementia care will be presented.

Aims of Study 2 - Part A

The community-based aspect of the paid care role, where workers share the personal domain of the care recipient's home will be investigated, with close review of interpersonal relationships and social connectedness. Investigating these areas will broaden the approach to capacity building by focusing on the importance of social connectedness in care work. Little is known about community dementia care workers' capacity and training needs, as well as how workers experience job demands and job resources, and P-O fit. Thus, the aim of the current study in this chapter is to adopt an exploratory approach to investigate the relationship between social and organisational psychological factors. There are

two objectives for this aim. The first objective is to develop a conceptual model for capacity building interventions that aim to support the dementia care workforce. The second objective is to review the implications of this model for intervention components that inform innovative capacity building intervention research and service delivery implementation in dementia care.

Method

Design

A qualitative multi-site exploratory-descriptive design was employed to provide in-depth information on dementia care workforce preparedness. Interpretive Phenomenological Analysis (IPA; Smith, Flowers, & Larkin, 2009) was adopted in the current study to examine how participants make sense of their personal and social world (Lyons & Coyle, 2008). An idiographic focus was applied to workers based in the community who support people with dementia as part of their employment. The research seeks to interpret the subjective experiences of dementia care workers by creating a detailed description of workers' values and beliefs about key vocational domains. To achieve credibility, one of four types of triangulation suggested by Denzin (1978) and Patton (1999), namely the theory/perspective triangulation was used, where multiple theoretical perspectives were applied to examine and interpret the data. This is consistent with best practice in conducting and reporting qualitative research as sourced in the Qualitative Research Guidelines Project (Cohen & Crabtree, 2006). A deductive approach was applied to data collection and analysis where information was categorised in detail according to key vocational domains. The interpretive phase involved content analysis of all textual data coded for emergent themes, identified and informed by theoretical concepts that assisted a rich description of the

resulting phenomena. Inter-coder comparisons were conducted to add rigor and reliability of research findings. The study conformed to Critical Appraisal Skills Program (CASP; 2002) and Bromley et al. (2002) criteria for conducting and reporting qualitative research, in that all of the criteria were fulfilled to indicate that the conclusions of the study are very unlikely to alter.

Participants

Twenty-five paid community dementia care workers were recruited over a six month period (April to October, 2010) from aged care community service providers in Tasmania, Australia as part of the Work 4 Dementia Project. The project was granted ethics approval from the Tasmanian Health and Medical Human Research Ethics Committee, EC00337 (reference number H10984) prior to recruitment.

Procedure

Participants were recruited from Home and Community Care (HACC) funded services in Tasmania, Australia. At the time of recruitment the HACC Program was a joint Commonwealth, State and Territory initiative. It funds basic maintenance and support services to help frail older people and younger people with disabilities to continue living in their community. Due to recent policy changes the HACC initiative is now operated solely by the Commonwealth and does not occur for the States of Victoria and Western Australia. Employees were invited to participate if they provided care and assistance to people with dementia and worked in the community care environment. Employees were eligible to participate if they delivered some form of care assistance or support to a person with dementia either a) in the care recipient's home, or b) completed home visits as part of service delivery, or c) performed tasks that enable the care recipient to

remain in the community, such as shopping, or d) a combination of these tasks. Employees working in residential care facilities were not included in the study.

Employees were invited to participate via use of flyers and brochures displayed in the work building. Potential participants registered their interest in the project via two methods; a) a telephone call or b) accessed a dedicated website where they completed a short form detailing their contact information. After registering their interest participants were contacted by the PhD candidate to discuss the project in more detail. If workers agreed to participate, a face-to-face or telephone interview was scheduled. Measures taken to minimise the risk of involvement in the project to workplace relationships included that all participants' information remained confidential and the workplace was not informed of workers participating in the project. In addition, interviews occurred away from the care workers' site of employment.

All participants read and completed information sheets, and, in addition to verbal consent, signed written consent forms (see Appendix A). The interviews comprised of intake questions about socio-demographic and employment information followed by a 30 minute standardised semi-structured interview exploring employees' values and views on their work (see Appendix B & C for Interview Schedules). A summary of the qualitative assessment used for dementia care workers is displayed in Table 9, including a description of the domains of interest, and examples of questions. For participants employed concurrently by two organisations, answers to interview questions related to their primary place of work. The interviews were conducted by the PhD candidate, who is a registered clinical psychologist. Interviews were recorded using a Philips Voice Tracer-LFH0622 and later transcribed for coding analysis.

Table 9

Summary of Qualitative Assessment for Dementia Care Workers

Domain (No. of Questions)	Description	Examples
Demographic information (9)	Age, sex, marital status, dependent children, education, cultural background, brief psychological history, qualification type and level.	<ul style="list-style-type: none"> • Highest level of education completed – primary, yr 10, yr 11, yr 12, TAFE, University. • In which country were you born, please specify? • Have you previously been to/or are currently attending counselling or psychological support? If yes when, and what was this in relation to?
Occupational information (11)	Years and type of dementia qualifications and training (previous training organisation/institute), orientation to profession, position title, income, employment basis (i.e. permanent full time), work hours per week, length of employment with current organisation, previous employment and training experiences, case load mix (i.e. dementia vs disability).	<ul style="list-style-type: none"> • On what basis are you currently employed with this organisation? Permanent full time, permanent part time, casual, other (please specify). • How many PWD would you see in a week? • Do you have a full, half or less than half dementia caseload? • What type of training have you completed? • Was there an induction program when you started work?

Domain (No. of Questions)	Description	Examples
Worker perceptions (22)	Worker beliefs, values about their role and duties.	<ul style="list-style-type: none"> • Describe a typical day in your job? • What do you think about the work you do? • Describe the support you receive at work.
	Relationship with people with dementia, and their carers and family member(s).	<ul style="list-style-type: none"> • Describe how you get along with the person with dementia and their family member(s). • What is important about the relationship between you and the person with dementia and family member(s)?
	Future direction of their service (i.e. work and role expectations).	<ul style="list-style-type: none"> • Describe how you think the “ageing crisis” and the increase in older people in the community will affect your work. • What do you think your workplace will look like in 5-10 years time? • How do you think your job will change, if at all? • If your organisation asked you to take on a new role what would you think?
	Training and professional development	<ul style="list-style-type: none"> • Do you feel supported by your organisation to complete training workshops/courses? • How are you supported by your organisation to complete training?

Domain (No. of Questions)	Description	Examples
		<ul style="list-style-type: none">• What do you think about the training you have done?
	Congruence between personal work goals and that of their workplace management and mission.	<ul style="list-style-type: none">• Describe the goals of your workplace.• Do you agree with the goals of your workplace?• What would you say are your goals at work?
	Attraction to workplace and future work intentions.	<ul style="list-style-type: none">• What attracted you to your workplace?• Do you intend to stay at your workplace in the future? If yes, for how long? If no, what could keep you at your workplace?

Data Analysis

Demographic and occupational information was entered into IBM SPSS Statistics 19.0 (2010) to produce descriptives of the sample. Qualitative data was managed through use QSR International's NVivo.8 (2008), computer software, designed for qualitative analysis, to facilitate greater consistency, rigour and speed in the analytic process (Bazeley, 2007). Three coding stages occurred to refine and confirm the phenomena identified in the data. The first stage of coding was to categorise interview comments into topics raised (i.e., nature of work, relationship with clients, work goals, support at work, training, attraction to work/future work, and future direction of dementia care). The second coding stage included matching categories to theoretical concepts, while identifying qualitative themes coded as nodes on a family tree. As new dimensions or themes became evident during the investigation the phenomena was highlighted by both discordant and converging themes (Robson, 2002). The third stage of coding involved a secondary coder to determine rates of inter-reliability and account for potential coding bias.

The node system is similar to a family tree (e.g., *Job demands* is the grandparent node, while *Practical caring role* is the parent node, and *Personal care* is the child node). Once all textual data was coded, a set of tables was created to provide example quotes of each node, used by the secondary coder for analysis and to calculate inter-coder reliability tests. Inter-coder reliability tests were conducted on the data. This process involved a secondary researcher (who was blind to the concepts of the Work 4 Dementia Project) to code 10% of the data (cases selected by random number generator). The researcher had training in NVIVO.8 and was provided with clear definitions of the node system.

Results

Sample Characteristics

Forty dementia care workers registered interest in the project, but eight of these individuals could not be contacted and three did not meet study inclusion criteria (reasons were; not currently working in dementia, $N = 1$; worked in residential care, $N = 1$; and worked solely with carers of people with dementia, $N = 1$). Of the 29 eligible workers three (10.35%) refused to participate. Reasons for refusal included; “too busy as moving house” ($N = 1$), “due to undergo surgery for a health condition” ($N = 1$), and thought the study “was about dementia and not so much about work” ($N = 1$). One worker failed to attend the interview and withdrew from the study.

Thus, 25 dementia care workers participated in the study. The workers were mostly middle aged females (\bar{x} age = 53 years, $SD = 9.61$) and they were employed for an average of six years ($SD = 4.33$) at their current workplace. The usual numbers of hours worked per week were on average 27 hours ($SD = 10.17$). Half of the female workers ($N = 11$) were from dual income families (married, $N = 10$; member of an unmarried couple, $N = 1$), and half ($N = 11$) were from single income families (never been married, $N = 4$; divorced, $N = 4$; widowed, $N = 2$; separated $N = 1$). Of the few male workers who participated ($N = 3$), they too were middle aged (\bar{x} age 55 years, $SD = 2.65$), but were on average employed for seven years ($SD = 4.91$) and usually worked 19 hours per week ($SD = 9.29$). Males mostly had never been married ($N = 2$).

While most single income families ($N = 13$) earned less than \$50,000 ($N = 11$), the reverse was true for dual income families ($N = 12$) who mostly earned above \$50,000 ($N = 8$). The majority of participants' household incomes were

above \$75,000 (N = 9), followed by \$35,000-49,999 (N = 6), \$25,000-34,999 (N = 5), \$20,000-24,999 (N = 2), 15,000-19,999 (N = 2) and \$50,000-74,999 (N = 1).

Majority of workers were born in Australia (N = 20) with a small minority born in England (N = 4) or South East Asia (N = 1). When asked “What is your occupation?” most participants answered “Support Worker” (N = 9). Other participants identified their occupation variously as, “Personal Care Assistant, Home Care Assistant, Community Carer, Extended Care Assistant, Lifestyle and Leisure Co-ordinator, Registered Nurse, or Divisional Therapist”.

Participants were recruited from seven organisations operating in the community care sector in Tasmania. The majority of workers were employed solely by one organisation (N = 16). Whereas a small number (N = 9) reported they were employed concurrently by two organisations. When starting employment most participants (N = 22) reported they attended a formal induction program, but a small number did not attend any formal induction to their work (N = 3). Approximately, one quarter of the sample reported they had attended professional psychological support in the past (N = 6). Most workers (N = 13) case mix included a majority of people with dementia in comparison to older adults, and people with disabilities as part of their paid role.

Workers were also asked about what types of training they would like to attend in the future. Topics stated by workers included “dementia and dementia up-dates, palliative care, train the trainer (training and assessment), nutrition for the client, career options, diversional therapy to manage behavioural problems of care recipient, medications, care recipient mental health, and caring for CALD patients and families”.

Table 10 reports the sample characteristics and shows information about participants' type of training they attended during their employment as paid community dementia carers.

Table 10

Demographic Characteristics of Dementia Care Workers

Characteristic	N	%
Sex		
Males	3	12
Females	22	88
Marital status		
Married	11	44
Never married	6	24
Divorced	4	16
Member of unmarried couple	1	4
Widowed	2	2
Separated	1	1
Education level		
Year Ten	1	4
Year Twelve	3	12
Certificate/diploma	14	56
University degree	7	28
Higher university degree	0	0
Qualification type		
Cert II	3	12
Cert III	11	44
Cert IV	8	32
Degree	3	12
Employment basis		
Permanent full-time	0	0
Permanent part-time	9	36
Casual	16	64
Past training experience		
Dementia specific	13	52
Aged Care	20	80
Manual handling	22	88
First Aid	22	88
Disabilities specific	3	12
Aged Mental Health	3	12
CALD specific	1	4

Characteristic	N	%
Recency of training		
Last 6 months	7	28
Last 12 months	7	28
Last 18 months	3	12
More than 2 years	8	32

Note. CALD = Culturally and Linguistically Diverse

Qualitative Themes

The semi-structured interviews were transcribed and coded for themes. On average, 57 themes were identified in each interview. The inter-coder reliability test across all themes revealed high average kappa coefficients of 0.93 and an agreement average of 99.55%. Further analysis was undertaken on the identified themes to create broad overarching commonalities with particular focus on theory driven concepts (i.e., communion, P-O fit, job demands, and job resources). Thus, three super-ordinate themes were identified: i) *Occupational communion*, ii) *Job demands* and iii) *Job resources*. Nineteen constituent themes were identified within the super-ordinate themes (see Appendix D, Tables 15, 16 and 17).

The overarching message around the community dementia care workforce thoughts and beliefs about their jobs was that they were highly satisfied in their jobs showing a strong attachment to their clients, while they felt more resources and training were needed to help them and others face the future. While workers enjoyed their jobs and the challenges of delivering support and care to people with dementia and their family members, they felt they were “undervalued”, “underpaid” and “under resourced”. Within each of the three super-ordinate themes are themes that relate to suggestions for improvements in the sector, all of which have important implications for organisational intervention. The themes are described with relevance for a conceptual model for capacity building and resilience.

Social Connectedness is Fundamental in Occupational Communion

Workers reported a genuine passion and commitment to caring that was focused on social interaction and relationship building, and that extended to both their clientele and work colleagues. Workers “loved” their jobs as they felt they

had a good match in their abilities and job duties. Social interaction was the best part of the work and many paid carers were attracted to the role as they “like people” and “enjoy the interaction”. The term occupational communion best described workers’ attraction to their jobs and their motivations to continue providing care, which was steeped in a sense of belonging and connection to others. Several types of occupational communion were identified and included *positive emotions* related to caring interactions, *rewarding relationships with clients*, *caring person-job fit*, and *social need-supply job fit*. Workers reported problems associated with two other forms of occupational communion; *desire for collegial social interaction* and *advocacy for client resources*.

Positive emotions formed part of the occupational communion theme and showed workers frequently mentioned positive affect as a result of their work and helping their clients. Providing this help through care and support to their clients was “extremely rewarding”, “exciting” and a “good feeling” for workers. For example, “the best part is, just being out there and helping people, and you really get appreciated, which is nice” (Worker 28). Workers commonly reported that they “loved” their jobs. Workers also consistently reported “feeling good” about being able to provide support to clients. For example, “it makes me feel good because I know, even if the money is not great, you put a smile on the peoples’ faces” (Worker 13). Positive emotions were also related to being reliable, for example, “they rely on you, and they know that when you come, you’ll fix the problem and you’ll help do something, and that’s a good feeling” (Worker 38). Being reliably able to “fix problems” or “help do something” may provide an opportunity for workers to build their self-efficacy and the experience of positive emotions about work. Continually meeting clients’ needs provides multiple

opportunities for mastery of specific caring tasks and may relate to job satisfaction.

A strong union and bond between the worker and their formal caring role was found. This connection extended to workers' rewarding relationships with clients, with reports of an attachment to and fondness of the people they cared for. Workers reported their "clients were beautiful" and used the affectionate term "love" when talking about care recipients. Some workers described their clients "like extended family" and acknowledged they enjoy "getting to know them". Bonds appeared to be strongest when workers felt they were a suitable carer for the client, highlighting the importance of a good match with clients from the workers' perspective.

The relationship with clients was paramount to the paid care role. Having a "trusting", "respectful" and "non-judgmental" relationship was important for workers so they could provide intimate care tasks such as showering and dressing. Some paid carers highlighted the need to share some personal information with their care recipients in order to build the relationship and to provide a connection they could continue to develop. This social tie was reported as an enabler to be able to ask clients to do activities they might not want to do (i.e., shower). Social "chit chat" was also reported to be useful to "help clients feel comfortable to receive personal care". Many workers felt "having a cup of tea" and "being social" was as important as a clean and safe home environment and thought that people with dementia were isolated and experienced loneliness. High importance was placed on social connectedness with clients by workers.

When discussing the rewarding aspects of the relationship, workers highlighted the importance of the continuation of the relationship with clients.

Workers' desired to remain providing care with the same clients (for long periods of time) so they could build an effective relationship that resulted in a stable supportive environment for the care recipient. One worker's comment highlights this with respect to their organisation's policy in comparison with other community care services:

At a lot of [work] places in this industry, you'd only work with the client for three months before they move you on to another one. So, you don't get that relationship, but with our lot, they're happy for us to go in and stay there, and keep, that relationship working. So to me, that's a big plus for us, we can get that continuity of care and that rapport, so [I'm] very lucky in that respect (Worker 19).

While the emphasis here is on a stable relationship and continuity of care, remaining with the same clients can also provide some stability and predictability for the workers themselves. Familiarity that comes from the development of a relationship over time was found to be important for care delivery, particularly for people with dementia. One worker (Worker 12) described how she avoided conflict in the caring role through familiarity with her clients "they know me and I know their routines so... I've got it worked out so I'm not going to cause any friction...because ...if you break their routine...that's when you're only going to have trouble". Therefore, the relationship appears not only to be important for the workers' feelings of reward, but also for the clients' quality of life, and for the workers ability to meet the client's needs.

A strong caring person - job fit was found to be a particular form of occupational communion and showed workers' abilities appeared to match the demands of the job. "Being easy-going" and "getting on well with people" were

traits commonly expressed by workers that related to reasons they “loved the job”. For most workers, these interpersonal attributes related to several areas, including working with clients, colleagues, senior staff and external health professionals. Workers showed they “love” the work they do because it is a good match to their own skills and abilities. Further, this part of occupational communion extended to include a match with workers interests and work preferences. For example “What I do like is not sitting in an office. I shoot around all over the place, all day” (Worker 18).

Another form of occupational communion was found to be social need-supply job fit. Workers highlighted a particular focus on the congruence between their psychological needs (i.e., a desire to care for others or have social interaction) and the job supply (i.e., delivering care and support to people). For example, “I had empty nest syndrome and this has just filled that void beautifully. I’ve got great clients. They’re just like an extended family and I’ve got people I can spoil rotten now” (Worker 19). Many workers reported their motivations for joining the care workforce related to their social needs, for example, “I work not because of money, I work for social interaction” (Worker 6). The emphasis of the social need-supply job fit is on the balance between the social need experienced by the worker, and the potential of the job roles to provide that need. Another example demonstrates this, “I knew that I needed to be with people. I wanted to work with people, and I quite enjoy older people’s company” (Worker 29). The social need-supply job fit shows that paid carers’ job roles form part of personal needs workers seek to fulfil.

The meaning of communion becomes apparent as workers showed they were motivated to help others to solve a greater community and societal problem

(i.e., that there is great need for caring roles in the community and limited workers to deliver such services). For example, workers described their work as “so necessary” and that they were “doing my bit” to help vulnerable community members. Acting as an advocate for clients was also part of occupational communion associated with the paid carer role. Workers spoke passionately about improving awareness about dementia and its symptoms in families, the general community and work colleagues, for the benefit of their clients (i.e., to reduce disease stigma and misunderstanding). This desire to help others was also expressed by workers wanting more access to funding for resources for their clients.

While rewarding relationships with clients formed part of the occupational communion theme, some workers also identified difficulties in forming relationships with people with dementia. In particular, workers reported that building a relationship with their clients with dementia was undermined by the symptoms of the disease. One worker stated:

If I describe my relationship...well it's hard because... if someone remembers you. There's things they say and you think “oh my gosh”... but you don't know if that's just by chance ... [Interviewer: So, now and again it might seem that they really understand who you are, and familiar with you, and other times it might seem that they're not?] Yeah. And that doesn't bother me, but... I guess that makes it challenging... to build a relationship (Worker 30).

A good match with clients formed part of occupational communion theme, but there may be implications for when there is an absence of this match or close connection. Professional caring when the connection is not strong or there is not a

good client match as perceived by the worker may lead to difficulties with the care relationship. This may have implications for the types of interpersonal interaction necessary for job satisfaction and result in more challenges for paid carers.

While the main role of occupational communion for workers related to their interaction with clients, it also extended to include social interaction with colleagues. Most workers reported positive forms of occupational communion related to interactions with clients, which contributed to strong job satisfaction. However, occupational communion that related to social relationships with work colleagues was found to be an unmet need. In particular, workers described a distinct need for improvements to be able to relate to other care workers as “the worst part of work is not enough interaction with other [formal] carers, it’s something that we really have to organise ourselves... to be able to share the ups and downs of life and also debrief. Talk about tricks of the trade... that would be really very useful” (Worker 8).

The effects of not having established patterns for collegial interaction in some cases led to negative effects on workers ability to engage in job development opportunities. A small minority of workers reported attachment to their clients while also holding mist-trusting opinions about co-workers’ skills to meet their clients’ needs. This was apparent when workers were required to re-schedule shifts in order to attend training, as some workers thought “other carers don’t know what I know about my clients” (Worker 6). Having little opportunity for interaction with co-workers provided few chances to de-mystify these perceptions.

Overall, the occupational communion theme portrayed a sense of happiness and positivity in workers to participate in job tasks that were inherently based in social interaction. While having compassion for their clients was

perceived to help workers to maintain their personal well-being and care skills, workers also desired collegial social interaction and professional care networks.

The Interpersonal Burdens of Job Demands

The *job demands* theme described care workers roles to deliver support and care that involve a degree of sustained physical and or psychological effort. The job demands theme consists of varying challenges of job roles, with some challenges more problematic for job satisfaction and distress than others. These were found to include *working with family members as mostly fine, the practical caring role, humanity and helping skills, emotional labour, blurred boundaries, working alone as a downside, and dealing with loss.*

Care recipient contact was a job demand that extended to include not only people with dementia but their informal carers and family members. Workers agreed that most family members co-operated to deliver care. However, sometimes family members were not available to help, seemed to ignore the dementia diagnosis, or conflict existed within the family and with care workers about approaches to care. Workers acknowledged the complexity of working with the family. For example “you can get into tricky situations when the son and daughter are having a disagreement and try get me on side” (Worker 10). Despite these challenges, a consensus amongst workers was that working with family members was “almost always fine”.

Part of the job demands theme was that workers reported varied roles made up of a diverse range of tasks. Commonly workers provided assistance with ADLs (i.e., personal care). Other roles included social interaction for the client, keeping clients active in the community, supporting family members, diversional therapy, and nursing. Central to the job demands theme was adaptability of workers to

deliver practical care tasks to suit individual client needs associated with disease symptoms. In particular, workers reported the necessity of “thinking on your feet”, “being alert” and “ready” to respond appropriately to clients’ mood or behaviour. For example one worker stated “you’ve always got to be one step ahead, and not know what they’re going to do next but try and predict, like if you’re going to say something, think about what you’re going to say before you say it” (Worker 12).

Good communication emerged as a job demand and workers reported a range of skills and abilities related to their interaction with clients. These skills were similar to the *helping skills set* as described by Egan’s (1998) skilled helper approach including “active listening”, “empathy” and an “open” and “non-judgemental attitude”. Workers reported applying these skills to work with people with dementia and their family members. These skills were found to be a particular job demand that required showing humanity and adopting helping skills.

Most workers made reference to occasions in their work role where they publically displayed certain types of emotions while hiding others, for the benefits of their clients. This experience was identified as a specific type of job demand called emotional labour. Workers spoke about the need to respect the client by showing interest in their lives. For example:

They know a lot more than, than you do, as far as life experiences go. A lot of them like to chat about the war, you know. It might sound boring as all hell to you, but at least look like you’re interested. You know, because that may be the highlight of their day (Worker 12).

This quote is an example of a form of emotional labour called surface acting, where the worker adjusts the way they appear to others by hiding their true emotional experience. Another worker spoke about a similar experience, and

stated “when I come out of somewhere I just heave a beautiful sigh of relief that I’m finished for that shift. Depending on what they’re like for the day, but you don’t tell them that” (Worker 14). Paid carers also reported that work was “emotionally draining” and “extremely tiring”. From workers reports it was identified that the caring role frequently involved emotional labour, where workers adjusted the expression of their emotions and regulated their feelings to best deal with this type of job demand.

Finding a balance between sharing some personal information, not placing additional burden on clients, and maintaining a professional relationship was confronted by workers when coping with blurred professional boundaries. Workers often reported they found themselves stretching the boundaries and completing extra duties for a client. For example:

You have to bend the boundaries at times, and it can be a difficult balancing act, because if you bend them too far you’re in serious strife...with one client, he was isolated, and off my own bat, I got him in my car and took him for a cup of coffee every now and then (Worker ID removed).

Workers’ motivations for blurring the boundaries appeared to relate to their desire to provide quality care to clients. In this case providing an opportunity for a social outing to relieve isolation. Finding the right balance in how to provide care was an additional job demand for workers caring role.

The physical environment of working in the community, travelling from one client to the next, and visiting people in their own homes was found to be isolating for workers and working alone was considered a downside. Workers also highlighted that when they enter the clients’ home to deliver care, there was a

potential for risks to their personal safety, for example, “I’m working alone and it’s a security thing too” (Worker 6).

Dealing with emotions such as sadness and grief was a challenge reported by workers and formed part of the job demands theme. Workers experienced burdens that were associated with their clients’ symptoms of dementia and included loss of functioning and changes in personality and difficult behaviours (i.e., delusions and aggression). For example, one worker reported the sadness she experienced in relation to the decline of her client’s functioning “yeah just sad that people... who have been judges and pilots, and doctors, are now, just not able to dress themselves” (Worker 1). When talking about dealing with death of clients workers mentioned emotive terms such as “shock”, “distressing”, “sad” and “difficult”. One participant (Worker 29) stated “when one of them passes on, it can be quite distressing. You know, especially when you’ve had someone for a long, long time. Yeah, and I don’t really see how people with a heart can get around that, to be honest with you. You do become attached, and they become attached to you”.

The job demands theme describes the many challenges faced by dementia care workers in their job roles. This theme showed that workers were consistently expected to rise to challenges such as being alert to changes in care recipients and the environment. Dealing with strong emotions such as grief and loss, and isolation, as well as navigating the boundaries of the professional care relationship to meet the needs of their clientele were also demanding aspects of the job.

Organisational Investment in Job Resources

The *job resources* theme included areas that are often associated with improving the workplace or workforce to reduce the negative effects of psychological costs of job demands. Workers reported many aspects of the job or workplace that contributed positively to assist in their abilities to cope with the job demands of the caring role. These included *attraction to the job* and work setting, *strong organisational commitment*, *sound perceived organisational support*, *good P-O fit*, and *satisfied with past training*, as well as *sound preparedness*. In addition to job resources that mostly assisted worker or workplace functioning, workers reported some areas where job resources were lacking and suggested ways to improve such resources. Aspects reported by workers that were problematic for reducing the negative effects of job demands were inconsistent quality in *leadership that was fine most of the time* and being *undervalued* and having *poor pay and conditions*.

Most workers were attracted to their job which was identified as a type of job resource. Workers were particularly attracted to the nature of the work and the setting. Commonly reported were their preference for the flexible nature of the work and a desire to be involved with people. Some workers gave work-life balance reasons for their attraction to the flexible and casual shift nature of the work. For example, “raising young children”, “returning to work after injury” and “move away from high stress hospital environment”. For some workers, motivation to participate in community care work was a career change related to redundancy. Most workers showed a past caring experience that was either personal, or within their family of origin and related this as a reason they were attracted to the work.

Many workers showed strong organisational commitment and intention to stay working for their organisation in the future which was identified as a job resource. Workers expressed feelings of loyalty towards the organisation. For example “I’m very loyal to them” (Worker 26) and “they’ve been good to me... they’ve done the right thing by me, so I’m going to look after them... I’ll stay until I retire” (Worker 19). Some workers reported, despite their own ageing, they would continue to work as a paid carer in the future, and would do so by reducing the number of hours they worked.

Another job resource identified for workers was good P-O fit. Workers reported similar personal goals to those of their organisations’ (such as the mission statement) making comments such as “my workplace goals and organisations [goals] pretty much align with mine, or I wouldn’t be working for them” (Worker 18). Workers appeared to be on the “same wavelength” as their employers when it came to delivering a service. Good P-O fit may act as a resource to contribute to worker satisfaction and intention to stay with the current employer.

Sound perceived organisational support was another type of job resource that showed workers felt their well-being or work contributions were valued by the organisation. For some workers, this included feeling supported to develop skills and knowledge via training activities. Workers identified the main reason their organisation valued their well-being was to maintain productivity. For example:

I know at work, when it comes to personal matters and stuff like that, they’re brilliant. You go to them, you’ve got a problem, you need time off, anything like that... they’ve got to look after you the best that they can so we can look after other people (Worker 19).

Some workers were supported to attend training (e.g., paid to attend a workshop and had their shifts re-scheduled). Most workers felt their organisations showed commitment to the workforce when requests were responded to and subsequent changes were made (e.g., providing alternative training times). The provision of information about training options (e.g., use of regular training newsletter) also contributed positively to workers' feelings of organisational support.

Organisational systems, for example, the ability to talk to a supervisor on the telephone if a worker had any concerns while they delivered care in the community, were reported as a positive job resource for workers. Most workers with good perceived organisational support said they were happy to take on new roles in the future. In addition, some reported they had already taken on new roles requested by their manager. Perceived organisational support may play a role in satisfaction of the workforce and also influence the willingness of workers to take on additional demands in the future.

Being satisfied with training was identified as a job resource theme, and most workers displayed a sense that ongoing learning was valuable and helpful for their roles. Commonly workers reported they benefited from the training. For example, one worker stated "you usually get something out of it" (Worker 40). Another worker commented "it's just... reinforcing what I already know" (Worker 19), while another said "it's all very practical" (Worker 11). Most workers felt they were easily able to access training as their organisations paid for their attendance, or assisted with re-scheduling shifts

Another type of job resource was sound preparedness. Workers' comments showed sound levels of awareness about the increases in the ageing population and dementia, and how this affected demand for services. Workers

knew of the problems they might face in the future and therefore had some level of preparedness to manage such changes. Few workers believed little change was inevitable, while many spoke of the “need for change”, “more care workers”, “increases for funding”, “ageing in place”, “more in home services”, and “specialised training”. Awareness of potential future challenges may help to build worker resilience to cope with job demands.

Part of the sound preparedness theme included some problems identified by care workers. While workers showed awareness about the ageing population they also showed a desire to be better prepared for the future. Workers wanted training in dementia for themselves and for other workers in the sector. One worker speculated about specialised training and knowledge in dementia:

Well, I’m hoping that more carers will be trained... with a bit more specialised knowledge, they can meet the needs of a lot of different people... dementia shows itself in different ways. You can’t treat people all the same way just because they have dementia (Worker 10).

This quote acknowledges the diverse nature and complexity of dementia and how the multiplicity of expression of the disease is experienced from the workers’ perspectives. Workers also expressed wanting more knowledge in medications. Overall, workers wanted more education and training in dementia and this desire was identified as a job resource that influenced workforce preparedness to cope with future changes. This notion of improving knowledge and awareness of dementia extended from the workforce into the general community. Workers wanted improvements in education and general attitudes about ageing and social inclusion.

Another part of the job resources sound preparedness theme was a general awareness and tentative hope for change in the system of care for people with dementia including “better co-ordination” and “more care packages”. Some workers understood organisational and workforce changes may take place in the future. For example:

There are going to be a lot more levels of people like from the boss down.

We will be interacting with a lot of co-ordinators not just a small amount and a lot of other services will have to come in place (Worker 6).

Workers wanted their clients’ interests at the forefront of any sector changes to care provision and did not want changes to be driven by economical savings reasons. Workers felt that more resources were needed such as programs and services and subsequent funding to assist with the demands of the future and their own preparedness to cope.

Leadership was identified as another job resource and most workers agreed that “leadership is fine most of the time”. However, some of the time, leadership from senior workers was varied, with workers experiencing a range in quality of advice and consultation. Inconsistency in the quality of support from senior staff was a common experience for workers. For example, there was variation in skills between leaders:

I had a supervisor who went off on maternity leave who was absolutely brilliant. You know you rang you queried something it was done. No dramas. But this, she’s a new lady, I don’t know if it’s settling time or what. I’ll give her that. I can ask other staff members (Worker 7).

Aspects that influence strong leadership may relate to consistency. Good leadership may be influenced by a senior worker’s ability to demonstrate

competence in their role. In particular, by completing core supervision tasks that affect care workers' job roles. Improvements in leadership, mentorship and supervision may be relevant for this workforce considering care workers' low level of qualification and training.

While strong organisational commitment was part of the job resources theme, some exceptional distinctive features showed emotional exhaustion, higher education, and poor P-O fit influenced workers intention to stay. Two workers expressed a desire to leave work. One wanted to leave as she did not "want to work with wall-to-wall grief anymore" (Worker 23). Whereas, the other commented "it's probably not the job I want to do forever" (Worker 30) and intended to leave after she graduated from a social work degree. One of these workers reported being unfamiliar with the goals of her organisation and intended to leave and reported they "couldn't give a stuff about them". A combination of lack of career pathways, high job stress and low congruence with employer values may influence workers' decisions when contemplating resignation.

Part of the sound perceived organisational support theme included factors that some workers found problematic. Workers reported feeling unsupported by their organisations when they perceived little support to access training, particularly for courses that were compulsory. A minority of workers mentioned the difficulty of missing their shift and pay to attend training. While the organisation might cover the training fee or cost of the trainer, this was perceived as less than supportive by some workers, for example "they do have regular training things, but you've got to do it in your own time. If you're working, well, you've got to do without that day's work" (Worker 11). It was a challenge for some workers to attend training as they could not take time off and had to make

child care arrangements. It may be important for employers to assist workers to access training if workers are to experience positive feelings of organisational support.

A job resource found to be lacking was job security. Workers reported they had poor pay and conditions had felt undervalued. Some workers felt they were not recognised or paid enough for their efforts, and there were little or no incentives to do extra shifts they often completed on the weekends. The job was consistently described as “insecure” with most of the workforce being employed on casual contracts. Upholding financial commitments such as a mortgage or contributing to superannuation was considered difficult. Reasons for this difficulty related to the unreliable nature of the work as “clients are not always there every week, which means that your pay goes down” (Worker 23). Reports were also made about wanting further assistance with running a car, other than the tax incentives provided by the government. Inconsistencies in the way resources were delivered to community workers were apparent. For example “there are health and community nurses and I think they are provided under the government umbrella with cars, but certainly in this sector there is nothing” (Worker 8). Feelings of disparity were integral to this theme. One worker stated “I’d like to think that it’d be... more of a diverse [workforce] it’s generally... middle aged women... and I think... that’s a reflection of how our society values that type of work” (Worker 33).

Poor conditions included the environment the workers operated within, such as the clients’ homes. Some workers reported that the homes were not set up in the best way to facilitate “ageing in place” and they wanted “more time with clients”. Speaking about the home environment one worker commented “... most

of our people are just in there for one hour, so you're in and you're out. So, you just bite your tongue and move on" (Worker 40). The comments made by workers showed they had poor job security which was identified as a job resource that many workers believed needed improvement.

Overall, the job resources theme highlighted several ways workers perceived their work to be supported by both personal and organisational factors. While generally this theme showed that workers perceived good access to resources to support them in their care roles, they also acknowledged specific areas that needed improvement. These included poor job conditions and resources they considered worthy of organisational investment.

In summary the qualitative results showed three superordinate themes; i) Occupational communion, ii) Job demands, and iii) Job resources. The occupational communion theme included a focus on workers' positivity about their job roles, which was based in social interaction with clients and colleagues. Compassion for their clients was perceived to help workers maintain their personal well-being and care skills. For some workers there was an unmet need for social interaction and engagement in professional care networks as part of the occupational communion theme. The job demands theme described the many challenges faced by dementia care workers in their roles. This included the expectation that workers had to rise to these challenges, such as being alert to changes in care recipients and the environment. Other demanding aspects of the job identified in this theme included, dealing with strong emotions such as grief and loss, and isolation, as well as navigating the boundaries of the professional care relationship. The job resources theme included how workers felt supported by both personal and organisational factors to complete their job roles. Workers

perceived good access to resources to support them in their care roles, but as part of the job resources theme they also acknowledged specific areas that needed improvement, such as poor job conditions.

Conceptual model for capacity building and resilience

Role of occupational communion in the conceptual model

Occupational communion may operate as a mediator in the work context to facilitate capacity building and resilience for the workforce (see Figure 3).

Workers perceived social interaction with colleagues as an adaptive way to cope with job demands such as isolation. Thus occupational communion may be a mediator between the effects of job demands on psychological well-being. Strong interpersonal ties and a good match with clients was reported to improve consent of care to recipients receive care. Occupational communion in this form may facilitate service delivery by acting as a mediator between job demands such as managing challenging behaviours and delivering quality care. Occupational communion may be an important factor to consider in the design of capacity building interventions for the dementia care workforce. Figure 3 displays the relationships between three factors. The central factor is occupational communion, as the presence of this factor influences the effect on workers of both the job demands and resources factor on the left, and capacity and resilience factor on the right. The pathway in the figure is from left to right, and in this way shows how organisations may improve capacity and resilience for their care workforces.

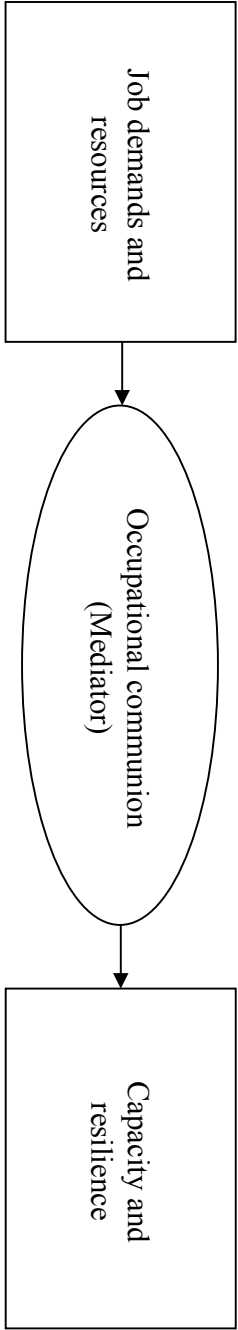


Figure 3. Conceptual model of occupational communion for capacity building and resilience

Role of job demands in the conceptual model

Job demands may be a predictor of poor psychological well-being, particularly if challenges of work are not mediated by job resources or occupational communion. The relationship between job demands and capacity and resilience may be indirect with occupational communion acting as a buffer against the psychological costs of job demands. For example, a sense of social connectedness in the work context may alleviate the challenges associated with blurred professional boundaries by providing a sense of collaboration to overcome the psychological costs. The same process may also be true for challenges such as isolation or dealing with loss. In this model, job demands that are based in social interaction such as recipient contact, emotional labour and helping skills may be best mediated by occupational communion to result in resilience. Job demands that remain unmediated may act as barriers for capacity building and workforce development. Further, the presence of high job demands without adequate coping mechanisms may contribute to problems with retention. Unmediated job demands may also influence quality care delivery, where workers are unable to manage challenges of the job (such as care refusals) due to a lack of adequate resources and social connectedness.

Role of job resources in the conceptual model

Job resources may be a predictor of adaptive psychological well-being, particularly when challenges of work are alleviated by factors such as organisational support via training and supervision. In this way, job resources and occupational communion may adopt similar processes in the conceptual model. For example, job resources and occupational communion may both act as a buffer against the psychological costs associated with challenges of the care role. In this

model, job resources that are based in social interaction such as supervisor support may be best mediated by occupational communion. When job resources are low or inadequate (such as poor job security), occupational communion may be particularly important to maintaining workforce resilience. For example, workers remained engaged in their work despite low pay and feeling undervalued because of the rewarding relationships they had with their clients and sense of duty to help others. When job resources are inadequate such as poor P-O fit this may contribute to worker dissatisfaction and intention to leave the current employer. For example workers intending to leave ($N = 3$) were not familiar with the goals of their employer and one worker gave emotional exhaustion as her reason intending to resign. It may be that job resources mediate job demands when resources are adequate. However, when resources are inadequate occupational communion may mediate job demands to result in adaptive workforce capacity and resilience. This model suggests that job resources alone may not be enough to mediate job demands in the context of community care work.

Chapter Five presented part of Study 2 (Part A) which employed a qualitative approach to examine a community-based dementia care workforce. The next chapter will report the other part of Study 2 (Part B). The findings are based on a quantitative review of the same workforce. An examination of dementia care workers' psychological adjustment to their work will be described in Chapter Six. The research in Chapter Six will illustrate how workers cope with the job demands of their care roles. In particular, an investigation of workers' intrapersonal and occupational coping resources will be presented following a clinical psychology case-based approach. By investigating employees' adjustment to work, target areas will be identified that may inform the development of capacity building interventions, and may complement the findings from the research reported in Chapter Five. Therefore, the study in the next chapter (Study 2 – Part B), will outline positive and negative profiles of adjustment for a community-based dementia care workforce, with a particular focus on employee resilience. The findings from both parts of Study 2 will also be discussed in the final section of Chapter Six.

Chapter 6

A Resilient Profile of Adjustment for the Dementia Care Workforce

(Study 2 - Part B)

“I’m a good thinker, especially with the dementia. I mean... you have to think on your feet. If it doesn’t succeed once, you have to say it in a different way... It’s a real challenge, but I love it”.

A comment made by a female participant about her job.

Capacity building in dementia care must form part of any national plan which intends to tackle the international health priority of dementia in the 21st century (WHO & ADI, 2012). High job demands and a low qualified workforce, characterise this sector (APPG, 2009). Additional workforce challenges include recruitment and retention issues where the existing employees themselves are not exempt from ageing and subsequent retirement (DCAC, 2009). The organisational factors that contribute to distress in this workforce remain relatively under investigated, especially in comparison to other workforces (i.e., nurses, police and rescue workers; Bonde, 2008; Darr & Johns, 2008; Edwards & Burnard, 2003; Van Der Ploeg & Kleber, 2003). An investigation of workers' psychological and occupational functioning will contribute to knowledge about intervention components that aim to enhance employee adjustment. Finding effective capacity building strategies that aid employees to cope with high job demands, may assist care services to prevail over the dementia epidemic.

Using a small selection of the dementia care workforce, the current study in this chapter will aim to develop a deeper understanding about the adjustment of workers to their roles. There are several objectives of Study 2 – Part B. One objective is to explore employees' experiences of occupational demands and resources. This will occur by utilising a clinical psychology approach to examine employees' intrapersonal coping, and psychological well-being. Reviewing the data in this way will extend the view of capacity building, to include employee coping and adjustment to work roles. Psychometrically sound measures will assess workers to firstly review overall group function and secondly to provide evidence for profiles of adjustment. This method is used frequently in the clinical psychology and psychiatry literature to describe individual adjustment to a chronic

stressor (i.e, medical condition; Charlier et al., 2012; Williams & Catalan, 2009) and has been applied to the occupational health field (Corneil, Beaton, Murphy, Johnson, & Pike, 1999; Huibers, Leone, Kant, & Knottnerus, 2006). It is often applied to reveal unique patterns of adjustment and coping that help inform psychotherapeutic treatment or human resource development approaches. This process is expanded further by reviewing intrapersonal coping in combination with occupational demands, and resources that apply to the organisational culture and environment. This approach, which combines two distinct disciplines, namely clinical and organisational psychology, adequately identifies areas for workforce development, while enabling comparisons between the current sample and general and clinical populations on indices of coping and mental health. A multi-disciplinary approach will combine the strengths of each area to form an overarching and holistic approach that attempt to best utilise limited resources during the current fiscal environment. Following this approach aspires to bring forth advancements in the field, paralleling the way psycho-oncology translational research has developed over the past ten years (Cao et al., 2011). Part of the agenda of the current study reported in this chapter, is to overcome barriers to workforce development by making research relevant and practical for translation to practice.

Employee stress in dementia care

Job stress has implications for retaining workers in employment, as well as affecting their ability to participate in work roles. Several meta-analytic reviews conducted over five decades have established the relationship between general health, psychological well-being, work stress and dissatisfaction (Bonde, 2008; Darr & Johns, 2008; Faragher et al., 2005; Kuoppala et al., 2008; Standsfeld &

Candy, 2006). While these reviews have mostly focused on general work settings, one review focused on the general health care setting (Michie & Williams, 2003), and another aged care (Pitfield et al., 2011). A systematic review of stress experienced by care staff of people with dementia found a lack of strong evidence across studies set in residential care (Pitfield et al., 2011). Two studies included in the review reported dissimilar prevalence rates of staff distress with Astrom, Nilsson, Norberg and Winblad (1990) finding 37% prevalence, whereas Kuremyr, Kihlgren, Norberg, Astrom and Karlsson (1994) reported 5% of staff were “at risk” from burnout. In contrast four studies reported low mean stress scores (Pitfield et al., 2011). The inconsistent results across studies were likely due to researchers using measures with poor or unknown psychometric properties. Generally speaking, dementia care workers experience some levels of job stress, however, the research evidence remains weak, with only one systematic review in the area (Pitfield et al., 2011), which only focused on effects for workers in 24-hour care settings.

Employee length of career in dementia and stress

Stress is experienced by staff working with people with dementia and they face challenges in their daily job roles. While early career long-term care workers in the United States experienced stress more than later career workers (employed more than two years), they also experienced more hopeful and person-centred attitudes about people with dementia (Zimmerman et al., 2005). Length of experience in care work seems to affect the way workers perceive their jobs, in particular early carer workers express overall higher levels of psychological arousal (i.e., presence of both distress and hope). It may be that being a carer for a long time reduces care workers’ level of intense reaction to job situations and

events. With more experience, care workers may develop coping strategies that reflect resilience to bounce back from ongoing work demands. *Optimistic realism* (Milhabet & Verhac, 2011), which is defined as the accuracy of an individual's outlook on the future, as opposed to hope, may be an attitude held by well adjusted later career workers. Intervention should consider length of employment when targeting certain psychological or training domains, with a potential to offer tailored programs for early versus later career workers. Similar to most research in this area, the findings by Zimmerman et al. (2005) relate to the residential setting, and whether or not the same findings are true for workers in the community sphere will be tested.

Organisational investment in job resources and employee stress

The care setting may play a role to mediate stress for some dementia care workers. A Canadian rural study found differences between nursing aides who worked in a specialised or a non-specialised care unit for people with dementia. Nursing aides in specialised care units reported lower job demands and strain, and less distress associated with exposure to disruptive behaviours than staff in non-specialised care units (Morgan et al., 2005). This may have implications for workers in an environment not optimised for care delivery. In Australia, in the regional community setting, workers reported problems with delivering care to people with dementia in their own home, particularly when environmental adjustments were not made to account for disability (Elliott et al., 2012 manuscript under review; SCARC, 2005). Organisational support that adequately provides resources for clients and workers to complete their job tasks effectively is likely to contribute to low stress levels and job satisfaction. Whether or not this applies to

the community care setting will be under review, with particular interest to issues around job demands and resources.

Social support and employee stress

A study from the Netherlands assessed the control and social support aspects of work in relation to job burnout for paid carers of people with dementia in group living environments. For these workers, environmental demands were low, as was burnout, while control, support and job satisfaction were high (Boekhorst et al., 2008). Social support appears to be an important factor for satisfied dementia care workers. Occupational communion is a particular form of social connectedness (Elliott et al., 2012 manuscript under review) identified in this workforce, and has been argued to be related to factors involved with attraction and retention of workers. Occupational communion may also serve as a buffer against negative adjustment and may assist workers to cope with psychological distress, associated with performing high job demands.

Disease specific employee stress

The most difficult aspects of working with people with dementia include coping with, and managing disruptive behaviours (such as aggression and hostility). The resistive, difficult and unpredictable nature of these behaviours were a challenge for Australian nurses working in residential care (Brodaty et al., 2003). Overall, most nurses were satisfied with their jobs, however, a quarter reported that working with people with dementia did not provide any job satisfaction. More negative than positive views were held by nursing staff in regards to people with dementia, in particular the five most prevalent perceptions of residents were that they were anxious, had little control over their difficult behaviour, were unpredictable, lonely and frightened, and or, vulnerable (Brodaty

et al., 2003). For dementia care workers, job satisfaction is multi-faceted and these workers can experience satisfaction in their job tasks and with the organisation while also experiencing negative perceptions of the clients they work with. Whether or not the same is true of workers in the community setting is under investigation in the current study.

The heterogeneous nature of dementia has many implications for the workforce and service providers operating within aged care. In fact, within the older adult group, Pachana and Helmes (2010) suggested that there is probably no other patient population that presents such diversity for health professionals than people diagnosed with a form of dementia. At palliative stages the types of dementia diseases appear similar. However, at early and middle stages of dementia the individual differences of disease symptoms, in combination with the variance across disease type, creates numerous complexities for the caring role of employees. In addition, roles and duties, and the extent of support provided by carers are contingent upon the nature and rate of disease progression. Thus, carers can face sudden and unpredictable changes in their roles. Employees care for multiple people with different types of dementia at varying disease stages, and therefore, operate within a sporadic work environment, where employees are continually required to adjust. Knowing how to provide training and capacity building to the dementia care workforce is complicated by the multiplicity of the disease itself. Acknowledging the complexities of dementia and the varied skill set required by employees is vital for training and education. Further, understanding how workers react to undertaking these roles is vital. Particularly for the determination of whether or not additional organisational supports and coping skills are required for optimum job performance of employees.

Occupational health interventions and employee stress

Occupational health psychology refers to the application of psychology to improving the quality of work life and to protection and promoting the safety, health and well-being of workers (Landy & Conte, 2007). Interventions with this focus may be appropriate for workers who experience distress associated with the high demands of working with people with dementia. There are two main approaches to interventions targeting improvements in worker well-being. One approach is to intervene by assisting workers to better manage their emotional responses to their work (i.e., individually targeted interventions). Another approach is to intervene at an organisational level to create better work practices to alleviate the stress associated with high demand and worker roles (organisationally targeted interventions).

Cognitive Behavioural (CBT) interventions in occupational health psychology that target individual function have best effects over and above organisational interventions, or alternative approaches, such as diary writing and relaxation (Richardson & Rothstein, 2008). However, implementation success is connected with the adaptability of the intervention to the workplace setting (Greenhalgh et al., 2004). Further, sustainability of the intervention often relies on the acceptability of the organisational culture to apply innovation (Lomas, 2004). From this research, it seems a combination of individual CBT and organisational approaches are most likely to apply to dementia care workforce development and warrant further research attention. The current study reported in this chapter offers some suggestions for potential areas suitable for interventions to target.

Research questions

The overall aim of the thesis is to broaden the understanding of capacity building with the objective to develop strategies for capacity building for the dementia care setting. The aim of Study 2 – Part B reported in this chapter is to develop a deeper understanding about the adjustment of workers to their roles. The effects of stress on workers, associated with the dementia care role, will be investigated using psychometrically sound measures. The research question under examination is whether or not similar patterns evident in the current occupational stress literature in dementia care (mostly focused on residential care), are also true for the community setting. A review of workers' patterns of adjustment will determine resilient and distress profiles. These profiles will inform the area of capacity building by highlighting potential areas that can be targeted by interventions that aim to enhance workforce development.

Hypotheses of Study 2 – Part B

Career status, such as length of time employed will be reviewed, as it is hypothesised that early career workers will show high levels of psychological distress and negative affect, whereas later career workers will show no or low distress and positive affect. Whether or not organisational support factors reduce worker stress will be examined. As it is hypothesised that those workers who feel supported by the organisation will show no psychological distress and exhibit positive affect in relation to their work. A profile of resilience may demonstrate organisational support at its core. The role of occupational communion in worker adjustment will be explored. It is hypothesised that workers with high psychological distress may experience an occupational communion need, where social interaction in the work environment is perceived to assist with coping with

high job demands. Community care workers' reaction to the high job demands (e.g., symptoms of dementia such as challenging behaviours and refusal of care), essential to dementia care will be investigated. The differences between workers who show positive and negative adjustment will be explored. Finally, it is hypothesised that profiles will highlight areas for intervention that enhance worker adjustment.

Method

As mentioned previously, the current study reported in this chapter is part of a larger investigation. Data was collected from the same participant sample reported in Study 2 – Part A. The procedure applied in the current study was the same adopted by Study 2 – Part A with an additional form of assessment. The additional assessment was quantitative and included a set of self-report measures on intrapersonal coping and occupational demands and resources. Twenty-five participants completed a questionnaire booklet that was either handed to them after an interview, or posted to their nominated address with a postage-paid return addressed envelope. All participants provided support to a person with dementia as part of their paid care role and were employed by community care services funded under Home and Community Care (HACC), which at the time was provided by both the State and Federal Australian Governments. The project was granted approval from the Tasmanian Health and Medical Human Research Ethics Committee, EC00337 (reference number H10984).

Design

A mixed method (i.e., qualitative and quantitative data) multi-site exploratory-descriptive design was employed to provide detailed information on dementia care workforce adjustment. A triangulation approach was adopted to

manage threats to validity and to enhance the rigor of research (Creswell, 2003; Fossey, Harvey, McDermott, & Davidson, 2002) . Three modes of data collection included; i) brief demographic and occupational intake interview, ii) semi-structured interview of worker perceptions, and iii) self-report questionnaires measuring the workers' intrapersonal coping and occupational demands and resources. Data from different sources that was qualitative and quantitative was analysed independently and their respective findings converged. A separate analysis occurred where worker profiles of adjustment were reviewed against the thematic data.

Measures

Qualitative assessment

All participants completed a brief demographic and occupational intake interview followed by a semi-structured interview of worker perceptions on key vocational domains (details are described in Study 2 – Part A).

Quantitative assessment: Self-report measures

Measures adopted in the current study (shown in Table 11) have been used extensively in the organisational health psychology literature. Intrapersonal coping resources and occupational demands and resources were assessed. In particular, workers' level of job satisfaction, congruence with work values, organisational commitment, and knowledge in dementia, occupational self-efficacy and psychological well-being were measured. The measures have published normative data, which enables examination of participants' functioning in the context of relevant occupational or clinical samples, and good reliability and validity. Coefficient alphas ranged from 0.71 (Kessler 10) – 0.95 (Occupational Self-

Efficacy Scale). Where normative data was unavailable, scores falling below the 25th or above the 75th percentile were considered clinically significant.

Table 11

Summary of Measures used to Assess Community-Based Dementia Care Workers

Domain	Measure	Description	Scoring (range)
	Reliability (Chronbach's α)	Participants asked to rate...	high score = Clinical cut off score
Intrapersonal coping resources			
Occupational self-efficacy	Occupational Self-Efficacy Scale (OSES; 0.92; Schyns & von Collani, 2002).	... ability to cope with work challenges on a six point Likert scale (1 = completely true, 6 = not at all true). (E.g., "As far as my job is concerned I am a rather self-reliant person").	(20-120) = low levels of occupational self-efficacy
Psychological well-being	Kessler 10 (K10; 0.71; Kessler, et al., 2003).	... the frequency of negative emotional states in the last month using a five point Likert scale (1= none of the time to 5= all of the time). (E.g., "about how often did you feel so nervous that nothing could calm you down")	(0-50) = high risk of mental disorder >20 <i>mental disorder</i>

Domain	Measure Reliability (Chronbach's α)	Description Participants asked to rate...	Scoring (range) high score = Clinical cut off score
	Positive and Negative Affect Schedule (PANAS; Watson, Clark, & Tellegen, 1988), (+ive 0.89 /-ive 0.85; Crawford & Henry, 2004).	... rate frequency of positive and negative emotions on a five point Likert scale (0 = none at all, 4 = extremely). (E.g., "excited/upset").	(0-20) PA= positive adjustment NA= depression
	Satisfaction with Life Scale (SWLS; 0.80 to 0.89; Diener, 1985).	... extent of agreement on seven point scale (1= strongly disagree to 7=strongly agree). (E.g., "In most ways my life is close to ideal").	(0-30) = high life satisfaction >25 <i>satisfied with life</i>

Domain	Measure Reliability (Chronbach's α)	Description Participants asked to rate...	Scoring (range) high score = Clinical cut off score
Occupational demands and resources			
Job satisfaction	Job Satisfaction Survey (JSS; 0.60-0.82 subscales and 0.91 total score; Spektor, 1985).	...level of satisfaction with their job on various areas (i.e., salary, promotion, supervision, fringe benefits, contingent rewards, operating procedures, co-workers, work and communication) using a six point Likert scale, (1 = disagree very much, 6 = agree very much). (E.g. "I like doing the things I do at work").	(36-216) = highly satisfied >144 <i>satisfied with job</i>
Job demands & resources	Job Demands-Resources Scale (JD-RS; 0.71 -0.90; Jackson & Rothman, 2005).	...job demands and resources on seven areas (i.e., growth opportunities, organisational support, overload, job insecurity, relationship with colleagues, control and rewards) on a four point scale (1 = never to 4 = always). (E.g., "Does your job offer you opportunities for personal growth and development?")	(40-160) = high job demands, high resources

Domain	Measure Reliability (Chronbach's α)	Description Participants asked to rate...	Scoring (range) high score = Clinical cut off score
Intent to stay	Organisational Commitment Questionnaire (OCCQ; Mowday, Steers & Porter, 1979), (0.89; Chew & Chan, 2008).	... their level of commitment to the organisation on a seven point scale (1 = strongly disagree – 7 = strongly agree). (Eg., “It would take very little change in my present circumstances to cause me to leave this organisation” - R).	(0-72) = high intent to stay
Congruence	Subjective Person-Organisation Fit Scale (SPOF; 0.88; Netemeyer, 1997).	... feelings of congruence between personal and organisational values on a five point scale (1= strongly disagree to 5 = strongly agree). (E.g., “I feel that my personal values are a good fit with this organisation”).	(4-16) = high congruence

Domain	Measure Reliability (Chronbach's α)	Description Participants asked to rate...	Scoring (range) high score = Clinical cut off score
Knowledge in dementia	Alzheimer's Disease Knowledge Test (Dieckmann et al., 1988), (ADKT; 07.1 - 0.92; Sullivan et al., 2003).	... level of dementia knowledge using multiple choice responses. (E.g. "Although the rate of progression of Alzheimer's disease is variable, the average life expectancy after onset is: (a) 6 months–1 year (b) 1–5 years (c) 6–12 years (d) 15–20 years (e) I don't know).	(0-17) = good knowledge about AD

Note. ADKT items 11, 14 and 18 were removed as they were indecipherable from the microfilm paper or not suitable for the Australian context. Further the original scoring method was not adopted as dementia biases held by workers were not a topic of interest. Instead correct answers were summed to form a total score, following a method previously adopted by Sullivan et al. (2007), R = item reverse scored.

Data Analysis

Questionnaire data was entered into IBM SPSS Statistics 19.0 (2010). Raw data was converted and tallied using Syntax to create total scores for all measures. Authors' instructions for scoring the psychological measures were followed. Data was analysed to produce descriptives of the sample. A case-based analysis was adopted whereby individual participant scores were reviewed for clinically significant adjustment across intrapersonal and occupational domains to create *worker profiles of adjustment*. Separate analysis occurred where worker profiles of adjustment were reviewed against the thematic data described by Study 2 – Part A. This analysis allowed for the convergence of both qualitative and quantitative data. Nvivo.8 (2008) software was used to create separate charts per theme as identified by workers. Charts were created for both super-ordinate and constituent themes to allow for close inspection of the data. Information was collected from the charts on the number of times a theme was referenced by each profile of workers. Calculations were made to show the average number of times a theme was identified by workers in either profile of adjustment (for both super-ordinate and constituent themes), as well as the proportion of workers in either profile that identified with each theme (constituent themes only).

Results

Participants were community dementia care workers (N = 25) with an average age of 53 years with the majority female (88%) and employed on a casual basis (64%; details of the sample descriptives are reported in Study 2 – Part A).

Group total scores on self-report measures

All dementia care workers completed a set of self-report measures assessing their level of job satisfaction, congruence, knowledge in dementia,

occupational self-efficacy and psychological well-being. The mean scores for the group showed adaptive functioning. In particular, the group had clinically significant adaptive functioning for occupational self-efficacy, job promotion opportunities, contingent job rewards and congruence with organisational values (as displayed in Table 12). Two outcomes approached significance, dissatisfaction with supervision and positive affect, where scores were all one standard deviation away from the normative comparison group. Overall, there was an absence of a group mean that indicated clinically significant poor functioning in any of the assessed areas.

Table 12

Dementia Care Workers' Mean Total Scores on Measures.

Measures	Range		\bar{x}	Std. Deviation	Qualitative Description
	Min	Max			
Occupational Self-Efficacy Scale	28	59	*42.44	8.46	Very high confidence in work ability
Kessler 10	10	24	14.72	3.78	Likely to be well
Positive and Negative Affect Schedule					
Positive Subscale	30	50	+1SD 39.80	5.51	High positive adjustment
Negative Subscale	10	23	14.24	3.88	Normal negative emotions present
Satisfaction With Life Scale	6	30	20.12	6.65	Generally satisfied - like some improvement

Measures	Range		\bar{x}	Std. Deviation	Qualitative Description
	Min	Max			
Job Satisfaction Survey	129	174	154.92	12.60	Overall satisfied with job
Pay Subscale	14	22	18.64	2.23	Normal satisfaction with pay
Promotions Subscale	19	23	*21.52	1.42	Highly satisfied with promotion
Supervision Subscale	14	19	-1SD 15.20	1.50	Dissatisfied with supervision
Benefits Subscale	14	22	18.48	2.22	Normal satisfaction with benefits
Contingent Rewards Subscale	14	21	*17.08	2.33	Highly satisfied with rewards
Operating Procedures Subscale	9	20	14.24	3.29	Normal satisfaction with operation
Co-workers Subscale	14	22	16.96	2.11	Normal satisfaction with co-workers
Nature of work Subscale	19	22	19.36	0.81	Normal satisfaction with nature of work
Communication Subscale	9	19	13.44	3.19	Normal satisfaction with communication
Job-Demands and Resources Scale					
Growth Opportunities Subscale	12	28	20.94	4.52	Normal growth opportunities
Organisational Support Subscale	33	68	53.80	10.63	Normal organisational support
Advancement Subscale	4	16	9.16	3.51	Normal advancement chances
Overload Subscale	15	28	21.96	4.15	Normal overload at work
Job Insecurity subscale	3	12	5.84	3.24	Normal job insecurity levels

Measures	Range		\bar{x}	Std. Deviation	Qualitative Description
	Min	Max			
Organisational Commitment Questionnaire	15	79	53.31	13.11	Normal intent to stay
Subjective Person Organisation Fit Scale	4	16	*12.37	3.92	Very high values match with organisation
Knowledge of Alzheimer's Disease Scale	5	13	9.20	2.24	Poor knowledge in dementia (54% correct)

Note. * Clinically significant adaptive function; ⁺ or -1SD = one standard deviation above or below the mean of the normative sample comparison.

Individual profiles of worker adjustment

Individual worker scores on all self-report measures were analysed for *caseness*, by firstly indicating adaptive functioning and secondly indicating poor functioning to form *global resilience* and *isolated distress profiles of adjustment* (see Table 13). Global resilient adjustment was considered to include workers who showed an absence of clinically significant levels of poor functioning as measured by the well-being questionnaires. In addition, workers with global resilient profiles showed clinically significant adjustment on various occupational resource domains and or psychological well-being. The isolated distress adjustment profiles included dysfunction in occupational demands and or psychological well-being domains, whereas global resilient profiles showed adaptive function in these areas. While workers in the isolated distress profile showed clinically significant levels of poor adjustment in occupational and or well-being domains, some workers showed positive adjustment in other domains (e.g., satisfaction with life or positive affect). The term “isolated distress” is therefore used to describe this profile to acknowledge this pattern of scores.

Global resilience

Overall, 64% of workers showed resilient profiles of work adjustment as measured by occupational resources and intrapersonal variables. Occupational resources included domains of occupational self-efficacy, satisfaction with pay, promotion and contingent rewards, congruence with workplace values, organisational commitment, knowledge of Alzheimer’s disease, whereas intrapersonal resources included general self-efficacy and positive affect. All workers with a global resilient profile showed clinically significant high levels of contingent job rewards and 94% showed satisfaction with opportunities for

promotion at work. Eighty-eight percent of resilient workers showed clinically high levels of occupational self-efficacy and 81% reported high congruence with organisational values. Fifty-six percent of resilient workers showed strong organisational commitment, 50% reported high satisfaction with supervision, 25% of workers showed high knowledge of Alzheimer's disease and 18% showed high satisfaction with pay. Only one worker (Worker 4) demonstrated high levels of general self-efficacy and one other worker (Worker 3) high positive affect.

Workers scoring positively on occupational resources and well-being were more likely to be in a committed relationship than not, and more likely to have worked for over five years, and were currently working above 20 hours per week. Most resilient workers had a household income of more than \$35,000, Certificate III or above and had attended training in dementia.

Isolated distress

Overall, 36% of workers scored poorly on some level of individual function on occupational demands or intrapersonal variables. These included domains of job advancement opportunities, congruence with workplace values, organisational commitment, satisfaction with life and psychological distress. Thirty-three percent of workers in the isolated distress profile (Workers 7, 26 and 27) had significantly low levels of congruence with their workplace values, as assessed by the SPOFS. Thirty-three percent of workers (Workers 7, 27 and 6) had significantly poor adjustment, as assessed by the K10. In fact, in clinical terms these workers scored in the *likely to have a mild mental disorder* range, meaning they were experiencing significant psychological distress. Another 33% of individuals (Workers 11, 27 and 18) reported dissatisfaction with life (one of these workers, 27, also had poor congruence and significant psychological distress).

Two workers (Workers 8 and 24) reported significantly low levels of job advancement opportunities as assessed by the JDR-A, and one worker (Worker 23) reported significantly low levels of organisational commitment. In addition, 66% of workers correctly answered less than half of the questions on the assessment of dementia knowledge, however, not significantly different from the normative population.

Workers scoring poorly on psychological well-being were not in a committed relationship (divorced, never married or widowed), employed on a casual basis, and had not undertaken training in dementia. These workers were more likely to be female, have Certificate III or below as highest level of education, have household incomes below \$35,000 and had employment for less than five years with their current employer. The individual reporting low organisational commitment (i.e., high intention to leave) also met similar criteria, however had worked for 10 years with their employer and held a degree and a Certificate IV. Overall, workers with poor function on occupational domains and well-being were more likely to hold Certificate III or above, did not completed training in dementia, and were not in a committed relationship.

Table 13

Global Resilience and Isolated Distress Profiles of Adjustment for Dementia Care Workers

Personal Background				Professional Characteristics			Occupational and Intrapersonal Adjustment		
Profile	Relationship Status	Total Household Income	Psych History	Profession	Qualification	Training in Dementia	Occupational Resources	Occupational Demands	Psychological Well-being
Global resilience	Mostly Married or Unmarried couple	Most \$35,000 or above	Minority (18.8%)	Mostly Support Workers (2, Diversional Therapists and 2 RNs)	81.3% Cert IV or below 18.8% Bachelor degree	Most yes	Very high occupational self-efficacy, high P-O fit, high satisfaction with specific job area (e.g., job rewards), good dementia knowledge.	Very low or nil	No distress & satisfied with life
	Mostly Unmarried not in committed relationship	Most \$35,000 or below	Minority (33.3%)	Mostly Support Workers (1 Diversional Therapists and 1 Co-ordinator)	66.7% Cert III or below 33.3% Cert IV 0% Bachelor degree	Most no	Very low or nil	Very low P-O fit, org commitment and job advancement	Very high distress & or low satisfaction with life

Convergent qualitative and quantitative results

Results for this section are based on data analysed in Study 2 – Part A, as well as quantitative data of the current study reported in this chapter. Firstly, qualitative evidence which supports the group quantitative outcomes will be reported. Secondly, a separate analysis of worker profiles of adjustment in light of qualitative thematic data will be reported.

Group outcomes

Group outcomes on self-report measures indicated dementia care workers had significantly high occupational self-efficacy. A very high level of confidence in work ability was also evident in qualitative data. In particular, one worker reflected a lack of desire to attend training in the future as she felt confident in her work. For example:

[Interviewer: What type of training would you like to do?] ... I don't think so. I think over the years with my hands-on experience I'm happy with what I know. I think it just comes down to the individual and how confident you are in the job (Worker 40).

Significantly high levels of congruence with work values were found, which were again reflected in the qualitative data. One participant highlighted the match between the organisation's goals and her personal goals, and stated that "keeping their independence, that's [the HACC service provider's] goal. And that's my goal" (Worker 7). Significantly high scores were found for job satisfaction relating to job promotion opportunities and converged with qualitative data. For example, a statement made by a worker about her career advancement opportunities "well, I've currently sought training to become an Enrolled Nurse, so, work's thoroughly supporting me. [Interviewer: and so how are they supporting you to do that?]

Changing my timetable, changing some of my responsibilities, and encouragement” (Worker 24). The same pattern was found for contingent job rewards as one worker stated her work was “extremely satisfying and it is so necessary” (Worker 30). Another worker showed strong job satisfaction, and stated “the best part is, yeah, just being out there and helping people. And, you know, you really get appreciated, which is nice” (Worker 28).

Although not significantly high, quantitative scores on positive affect approached significance, with workers talking about the positive emotions she or he experienced as part of the work. For example:

She trusts me and I think when you work in the way we do, you develop a trust[ing] relationship and they know they rely on you, they know that when you come, you’ll fix the problem and you’ll help do something, and that’s a good feeling (Worker 38).

Scores on satisfaction with supervision showed a similar pattern approaching significance, but in the opposite direction suggesting a trend of workers dissatisfied with supervision and leadership. Workers qualitative comments reflected a level of dissatisfaction with leadership/supervision, and one worker stated “they say they support us, but if you try to talk to anybody you realise they’re always very busy and you’re a bloody nuisance really” (Worker 11).

Worker adjustment profiles and qualitative themes

A final analysis was conducted to compare workers with *resilient adjustment profiles* to those with *isolated distress profiles* on qualitative themes. This analysis allowed for the convergence of both quantitative and qualitative data for both super-ordinate and constituent themes.

Overall, at the super-ordinate level, resilient workers consistently identified more themes than workers with isolated distress. On average, resilient workers identified with the occupational communion theme 3.94 times, while workers with isolated distress 3.56 times. For the job demands, theme resilient workers identified an average of 10.38 times, in comparison to an average of 7.66 times for workers with isolated distress. While resilient workers identified with the job resources theme an average of 16.0 times, workers with isolated distress identified an average of 15.22 times. Due to the closeness of the difference in these results, further inspection of themes occurred at the constituent level.

The same pattern was found on review of constituent themes where resilient workers consistently identified more themes than workers with isolated distress, with some exceptions for specific types of occupational communion. Namely, collegial social interaction and rewarding relationships with clients, as well as specific job demands, and job resources. Differences were found for the two profiles for the job demand of working in isolation, and poor pay and conditions (lacking job resource) and the true job resource of leadership.

A lower proportion of resilient workers reported need for social support from their colleagues and less focus on rewarding relationships with clients (13 and 31%) than workers with isolated distress (44 and 66%). This demonstrates that resilient workers have adequate levels of these specific types of occupational communion. Occupational communion may have implications for positive adjustment and work performance. In addition, occupational communion may be a component that can assist workers with isolated distress to cope. For example, a resilient worker described how she coped with her job by seeking some social and practical support from the organisation:

If I don't feel like I can deal with it then I will go back to work and say - look, I don't think I can cope with that client, I think you need to get a different carer in. So it all depends on how you feel you can deal with that person... If you need to sit down and talk one-on-one with your boss, you want to have a bit of an 'I can't cope session, what do I do?' they're there to help you through that (Worker 12).

Actively seeking social support to debrief about particular work situations appears to be an effective way of coping for this worker, who identified with the resilient profile.

Working alone as a downside was identified by a lower proportion of resilient workers (44%) than workers with isolated distress (25%). Workers with positive adjustment may not notice the burdens of working in isolation in the community setting, as much as workers experiencing personal or work related distress. In fact, some workers wanted the isolation to be rectified. For example, one worker with an isolated distress profile stated "we all work in isolation out in the community, so I guess that's a gap. That we don't often meet each other... so... that's what they could do differently" (Worker 18).

Feeling undervalued and having poor pay and conditions was identified by a lower proportion of resilient workers (38%) than workers with isolated distress (44%). Part of the isolated distress profile included low financial security with most workers earning below \$35,000 per household per annum. Workers want support in this area to be able to perform job tasks. For example, one worker with an isolated distress profile stated "I think the government maybe from a monetary point of view hasn't realised how we could do with a bit more support like

running your car. You couldn't do the job without a car" (Worker 6). Having financial security is important for workers' resilience.

In addition, leadership was identified as a job resource by a lower proportion of resilient workers (81%) than workers with isolated distress (100%). Leadership may be more important for workers experiencing isolated distress, as guidance and mentorship may help to alleviate burdens associated with work tasks. For example, a worker with an isolated distress profile stated "my supervisor said nothing. That's where I felt let down, because she should of come to the party and said..." (Worker 7). Further, the quality and consistency of supervisors and co-ordinations may be more important for workers with isolated levels of distress.

Isolated distress and organisational commitment

Congruence with workplace values, job advancement opportunities and commitment to the organisation were all very low for some workers with *isolated distress profiles*. In one case, nothing would keep the worker in her job in the future, "I don't want to work with people who are disconnected. I don't want to work with wall-to-wall grief anymore... regardless of the pay, regardless of whether you have continuous flow of clients... I've had enough" (Worker 23). The same worker scored very low on organisational commitment and indicated no care for the organisation and stated "I suppose their goals are to deliver... care where it's needed. I suppose that's their goal. I don't really give a stuff about them actually. Isn't that terrible". This worker illustrates that low agreement and care for the values of the workplace combined with low organisational commitment are likely to contribute to intentions to leave the workplace in the future. When asked if the worker intended to stay at the workplace in the future, she answered,

“No...I’ve had enough of the lack of continuity of clients and pay. Ten years is long enough to work with people with dementia, emotionally it’s very draining”. The high occupational demands of emotional strain and job insecurity were highlighted as a reason to leave work.

Discussion Study 2 - Part A and B

Dementia care work is one of the fastest growing occupational groups worldwide and international peak bodies (WHO & ADI, 2012) advocate workforce preparedness to sustain and support this occupational group. The findings from Study 2 inform the design of interventions to build care workers' capacity and resilience to face the challenges of the dementia epidemic. The concept of occupational communion was identified and described in Study 2 - Part A. Occupational communion is defined as a sense of belonging based in social interaction at work that can assist adaptive coping. To date, this is the first study to identify this construct in paid carers. The findings from Study 2 – Part B showed overall, dementia care workers reported positive function, but some cases showed workers with isolated distress. An evaluation of caseness showed, two distinct adjustment profiles characterised by scores on psychological measures that reflected i) global resilience and ii) isolated distress. While the results from Study 2 were presented separately, here the implications for capacity building strategies are discussed collectively.

Occupational communion where the motivation to participate in paid care roles was based in social interaction and relationship building was found for a mainly female sample. While the sample of Study 2, is consistent with demographic characteristics of workers internationally (Figueriredo, 2011; Hussein & Manthorpe, 2011; Martin & King, 2008), occupational communion may be particularly relevant for women. Whereas Helgeson (1994) suggested agency as a positive male gender related trait that describes a healthy self-focus. Underlying care workers' high commitment to their clients appears to be a social need that is based in attachment and a sense of belonging and may be particularly

relevant for women's careers (Ellery-Brown, 2011). Findings from Study 2 – Part A suggest that extreme forms of communion such as unmitigated communion (Helgeson & Fritz, 1998) are present in the work setting, where employees focus on others (i.e., clients or colleagues) to the exclusion of their own interests. For example, the blurred boundaries theme (viewed as a job demand) showed that some workers were willing to risk their employment by defying organisational rules to deliver care that met clients' needs (e.g., taking client for an outing to alleviate social isolation). Occupational communion may be a key factor to consider for interventions that aim to attract, train and retain a care workforce to deal with the dementia growth in the aged care sector.

Social support (e.g., *job demands-control-support model*; Daniels, 1999) differs from the concept of occupational communion as it does not relate to social ties with clients. In this aspect, occupational communion does not mirror social support as it has professional limitations and is not a mutual and equal relationship, as workers feel they cannot burden clients with their own personal worries or concerns. Instead the connection with clientele relates to social exchange where workers can be stimulated by participating in a relationship where they can meet a psychological need and feel privileged to learn about the care recipient in order to deliver quality care. A sense of belonging is linked to workers' beliefs in their natural ability to care and "others focus" which is reinforced by their job roles and interaction with clientele and colleagues.

There has been a small amount of prior research that has explored aspects of communion and the workplace. One study investigated interactions between nurse assistants and patients with severe dementia and found a sense of mutual togetherness was central to care exchanges (Hansebo & Kihlgren, 2002). Part of

this togetherness took the form of “deep communication for communion” (p. 225), which not only involved a “deep relationship between nurse and patient” (p. 230), but led to positive care outcomes such as nurses’ turning care refusals into consent to care (Hansebo & Kihlgren, 2002). While these qualitative results were based in the residential care setting and did not relate to care workers supporting patients with mild to moderate dementia, there are similarities with the findings of Study 2 – Part A. Client focused social ties (occupational communion theme) appear to enable care workers to perform challenging care tasks that form part of high job demands. For example, “social chit chat” to help clients feel comfortable to receive care and less likely to refuse care. Therefore, occupational communion may be important for employees’ job performance, especially when performing care tasks that are based in social interaction. While Hansebo and Kihlgren (2002) discussed communion as a small part of a larger overarching concept, “balancing for togetherness” (p. 231), they did not contextualise this concept at the interface between social and organisational psychology.

Seeking communion may serve as a protective factor for employees at work as there is tentative evidence that workers may strive for communion as a coping strategy to deal with job stress. Halbesleben and Bowler (2007) found that when workers experienced emotional exhaustion, they sought to increase their resources in communion (such as social interaction with colleagues). While findings by Halbesleben and Bowler (2007) were based on fire-fighters, they appear to support the results of Study 2 – Part A. In particular, previous research supports the finding that indicated community dementia care workers desired social interaction with colleagues (part of the occupational communion theme) to cope with high job demands, such as working in isolation. A similar pattern was

also found for the supportive care sector as social relationships were perceived by disability service workers as integral to the ideal organisational culture (Hatton et al., 1999). Therefore, implications suggest that communion in the work context where there are high demands, may serve to buffer against poor employee well-being and play a mediating role in job performance and be beneficial for organisational culture.

A full description of the unique job demands and job resources for community dementia care workers was identified and informed by the JD-R model (Demerouti et al., 2001). Job demands highlighted the multiple challenges of the paid care role. Job demands were previously found to refer to aspects of the job that required continued physical or mental effort and resulted in certain physiological and psychological costs (Demerouti et al., 2001). Whereas, job resources highlighted several ways employees perceived their work to be supported by both personal and organisational factors. Job resources were found to contribute to and maintain worker well-being, and facilitated achievement of work goals, reduced the costs of job demands, and encouraged personal growth (Demerouti et al., 2001). The job demands and job resources themes highlighted by Study 2 – Part A, help to inform policy makers on potential areas for capacity building interventions, that are aimed at worker skills and capabilities, as well as organisational responsibilities.

The Senate Community Affairs References Committee of the Australian Federal Government (SCARC, 2005) reported similar findings to Study 2 – Part A. SCARC described community care workers as experiencing low pay, a lack of career pathways, an isolated work environment, occupational health and safety challenges associated with working in the client's own home, and an ageing

profile. The committee argued that these factors contribute to high rates of worker turnover in the sector. In addition, a workplace culture still exists, despite Australian Federal Government initiatives such as the Aged Care Education and Training Incentive Program (DoHA, 2011), that life experience and an attitude of commitment is sufficient for effective and efficient care workers (Booth et al., 2008). This assumption, in combination with care workers' training barriers, such as the need to cover work shifts, is a likely obstacle for skill enhancement of the workforce for the future.

Capacity building interventions may adopt components informed by the three main themes identified by Study 2 – Part A; namely occupational communion, job demands and job resources. In particular, components that derive from the occupational communion theme may focus on social interaction at work. These may include regular meetings between workers to help cope with job demands, such as isolation. Components may also include training or group discussions about how to establish and maintain relationships with clients to facilitate quality care (e.g., care consent). Interventions informed by occupational communion that aim to improve recruitment may include components that focus on maintaining positive perceptions of work-life balance to attract potential employees. These may also focus on matching the social need of potential employees to the supply of the job.

In the conceptual model, job demands may be a predictor of poor psychological well-being, particularly if challenges of work are not mediated by job resources or occupational communion. Components informed by the job demands theme may include a focus on several areas, such as emotional regulation and stress management strategies to cope with emotional labour and grief and loss.

Another component suitable for capacity building interventions may include education about dementia to manage behavioural problems and improve workers' capabilities of adjusting to changes in clients' needs. This is especially true, when one considers that only 52% of the sample attended dementia specific training. This was despite most employees all working with people with dementia. Education may extend to include a focus on community awareness to reduce stigma and lack of knowledge about the disease and available services, which in turn, may contribute to a collaborative approach between workers and informal carers and patients. Providing guidance and strategies on how to manage professional boundaries may also be part of interventions informed by the job demands theme.

In contrast, organisational supportive functions informed by the job resources theme may include making improvements to perceived organisational support (POS) by providing financial and practical support to access training. In this respect, developing leadership capabilities to ensure quality and consistent supervision and mentorship may also form part of intervention components that aim to enhance capacity. Other components may include acknowledging and valuing workers' efforts through incentive or recognition programs. Further, enhancing P-O fit through induction or orientation programs may promote congruence between worker and employer values and may be essential for workforce development. Some other organisational support resources that may be suitable for intervention include improving job security, increasing practical resources that adhere to ageing in place and overall system improvements for better collaboration. However, these components may be more reliant upon funding structures and governmental policies.

Results from Study 2 – Part B showed on average, community dementia care workers showed high occupational self-efficacy, high job satisfaction in contingent work rewards and promotional opportunities, as well as high congruence with organisational values. Although not significant, two trends showed workers experienced positive affect, but they were dissatisfied with supervision. Global resilience profiles showed positive adjustment across a range of occupational and intrapersonal domains to suggest that resilient workers were extremely confident in their work ability, believed their personal values matched those of their employer, and found their jobs satisfying and rewarding. In comparison, workers with an isolated distress profile fared much worse, as job resources were low (poor job advancement opportunities and miss-match in personal and work values), and for some, levels of psychological distress were high (enough to warrant psychological treatment). Demographic and occupational differences between profiles showed disparity across workers. Fittingly, resilient workers were more likely to have longer length of employment (five years and above), be in a committed relationship, hold higher levels of education and qualifications, earn above \$35,000 household income, and have dementia specific training. Improving workers' job resources and distress levels to cope with high demands is likely to contribute to workforce preparedness for the dementia epidemic.

The first hypothesis of Study 2 - Part B was supported and showed that career status (in terms of length of employment) influenced how workers experienced distress. In the current study reported in this chapter, later career workers were more likely to identify with a resilient rather than an isolated distress profile supporting findings by Zimmerman et al. (2005). This has

implications for orientation programs and initial stages of recruitment for the community dementia care sector where early career workers are likely to experience distress associated with job demands. Considering the integral role stress plays with job dissatisfaction and intention to leave, interventions that pay particular attention to early career workers may be warranted.

While there was no direct finding of high organisational support in the current study, some results suggested leadership, a type of organisational support, may be more important for workers with isolated distress than global resilience profiles. Guidance and mentorship may be a greater need for workers with isolated distress to help alleviate burdens associated with decision making and problem solving as part of the paid care role. Further, leadership in this workforce often involves supervision, where workers are able to seek advice and support that extends to include debriefing and social support from a more senior work colleague. Therefore, organisational support in the form of collegial interaction and guidance appears to be integral to the performance of community-based dementia care workers.

Social interaction with colleagues and rewarding relationships with clients appeared to be more important for workers with isolated distressed as they experienced higher needs in these areas than resilient workers. Further, workers with isolated distress experienced working alone as a downside more often than resilient workers. This supports the hypothesis that workers with high psychological distress experience occupational communion as an unmet need. Social connectedness or occupational communion appears to be a valuable resource for workers, who perceive social interaction as a coping resource. This has implications for service providers for retention of workers. Providing

organisationally run opportunities for collegial interaction may help those workers to adjust to their job roles, and also reduce their likelihood of leaving due to dissatisfaction and distress. In this way, occupational communion may act as a buffer against the negative effects high job demands.

The clinical psychology literature assists to explain the group finding of overall adaptive function, considering workers reports of high occupational self-efficacy. Individuals with high confidence to cope with chronic stressors have better adjustment than those with low confidence (Turner et al., 2007). The same processes may be at play with regard to workers' occupational self-efficacy. It may be that intrapersonal protective factors for workers to cope during times of high demand include not only high occupational self-efficacy, but also other factors. These other factors may include secure personal relationships, further education and training, satisfaction with life and low levels of psychological distress. Thus, interventions that target these domains may enhance worker well-being and commitment to work.

Organisationally focused intervention approaches identified by Study 2 – Part B included leadership training for managers and supervisors aimed to improve consistency in responses and quality of advice and mentorship. Promoting collegial social contact for employees to debrief, and reduce the negative impact of working in isolation by scheduling regular team meetings was also identified as a way to improve the sector. Improving pay and conditions, including developing clear career pathways and organisational recognition of worker's care efforts were also found as potential areas to target. Further, consideration of career status, where early career workers appear more vulnerable

to distress highlights the importance of orientation programs and mentorship in the sector, particularly at the beginning stages of employment.

Limitations of the Study 2 include the generalisability of the findings to the broader dementia care worker population. Study 2 focused on a small selection of the community-based dementia care workforce in Tasmania, an island state of Australia. Tasmania is the 26th largest island in the world, but it has a relatively small population of just over 500,000 people (ABS, 2012 – Part A). Two years ago, Tasmania became the state (alongside South Australia) with the highest proportion (15.6%) of people aged 65 years and over in the nation (ABS, 2010) and is therefore, expected to have a higher proportion of clients accessing home care than most other States (AE, 2010). Further, island communities, like Tasmania, and regional areas are particularly vulnerable to workforce shortage (The Allen Consulting Group; ACG, 2007; Demographic Change Advisory Council; DCAC, 2009).

Despite the location of the study, comparable workforce characteristics were found to that of other national surveys in Australia, the United Kingdom and the United States (Figueriredo, 2011; Hussein & Manthorpe, 2011; Martin & King, 2008), with the exception that most care workers had casual rather than part-time employment status. In addition, the percentage of workers (20%) with poor psychological well-being in Study 2 matched that of the general population, as 20% of Australian adults experience psychological problems such as mental illness in any year (ABS, 2007). A lack of resources and access to funding experienced by HACC services to deliver support in a regional area may help explain the difference between the employment status of employees in the current sample and national data. Further, a convenience sample was employed whereby

self-referral to the study occurred. Therefore, most workers experiencing burnout and actively contemplating leaving the sector may not have participated.

The comparison, between profiles based on quantitative data in Part B may be influenced by the numbers of participants in each profile group, and is considered a limitation of the study. There was a greater proportion of the sample in the resilient group, which may have biased findings. This particularly influenced the convergence analysis and must be taken into consideration when interpreting the results. Future research through replication studies are needed to closely examine a larger number of the workforce that experience distress in the community-based dementia care setting. Despite using psychometrically sound measures, some of the main findings were based on subscales (e.g., satisfaction with job promotion and contingent job rewards) which can be less reliable than total scores. However, alpha coefficients for these subscales were not below 0.73 (Spector, 1985). Despite this, the uses of subscales can increase the likelihood of type II errors.

Strengths of Study 2 included the rigor of qualitative coding and the application of multiple theoretical concepts (Part A). Most previous studies exploring communion in the work context did not have a dementia focus and were not set in the community, and had adopted the use of surveys. By applying a qualitative focus to Part A, described in-depth the issues most pertinent for community dementia care workers. The relevance of social and organisational psychological theories for sustainability of the dementia care workforce was found to inform capacity building strategies. This approach is unique in the formal care literature, and a multi-discipline approach provides a collective strength to determine the best ways to prepare the dementia care workforce for future

demands. Another strength of Study 2 is the use of well validated and reliable psychometric tools to assess worker psychological function. Further, applying the case-based clinical psychology approach enabled the comparison of dementia care worker function to clinical and normative samples. This approach is distinctive within dementia care research.

Occupational communion may be particularly relevant for womens' caring careers, and future research is needed to explore the relevance of this concept for men in formal care. In addition, future research must address the under representation of the community dementia care setting in the literature. Randomised control trial studies are needed that target both worker and organisational outcome domains highlighted by the themes of the current study. To determine reliable change associated with interventions that target occupational communion, further investigation is required on measurement approaches of this concept. Developing assessment tools or adapting existing tools that measure agency and communion to the work setting should be included in future research. Whether or not intervention components informed by occupational communion, job demands and resources themes are effective to improve skills and capabilities for all workers or a subset of workers is also relevant for future research. In turn, whether or not outcomes from intervention research can be replicated through service implementation and translated into practice is of high priority to improve the organisational capacity of services to cope with the predicted high demands in the aged and dementia care industry.

Community dementia care workers genuinely feel "at home" when working with clients. Workers have strong social ties that contribute positively to the continuity of quality care. Despite this, workers experience an overall

imbalance in their sense of belonging at work, with particular regard to their professional identity and relationships with colleagues. While a physical base may not appear important for community care workers, a strong social work network may offer the foundations essential to a healthy and productive workforce. Providing equilibrium in occupational communion where employees feel a true sense of belonging at work, may create the security the paid care workforce needs in order to attract, train and retain carers to cope with the ageing population.

Overall, dementia care workers showed good fit with the values and goals of HACC services and similar findings have been found in effective organisations (O'Driscoll et al., 2003b). It maybe that enhancing congruence assists not only in effective function of organisations, but also assists to enable preparedness for organisational change. While the current study did not undertake any organisational assessments independent from workers' views, it was still able to offer an insight as to the preparedness of workers to cope with high demands. Those workers likely to experience distress in the face of high demands may be those less engaged with organisations values and future directions. An extension of the research may be to consider the managerial and organisational leaders' views and further evaluate service delivery to determine a multi-level view of capacity building and resilience.

By identifying profiles of resilience and distress, factors that assist workers to cope or instead that lead to distress can be identified. Such factors may be targeted by human resource development interventions to improve workforce capacity. The results of the current study reported in this chapter, raised several suggestions for specific intervention components that form part of an agenda for future research in innovation implementation and evaluation. Domains that would

be suitably targeted by individual CBT approaches include psychological well-being, which may be improved by psycho-education about the stress response and stress management strategies to deal with and prevent symptoms of distress, as well as how to activate social supports at work. Raising education levels and qualifications in the sector may also improve resiliency of the workforce by having strong knowledge and self-efficacy that will contribute to preparedness. In particular, dementia training for workers appears to be important considering workers with isolated distress profiles were more likely to have no training in this area, despite regularly providing support to people with dementia and their informal carers.

While other methods of inquiry have found similar results to Study 2 (Brodaty et al., 2003; Morgan et al., 2005; SCARC, 2005; Zimmerman et al., 2005) no rigorously tested human resource development interventions in the community setting for dementia care workers has been conducted (Elliott et al., 2012). Considering the overwhelming trend towards ageing in place and subsequent demands this places on community care services (such as HACC in Australia) research in this area is greatly needed. If resolutions on human resource issues such as recruitment and retention are to adequately move forward, attention must be focused on several areas. These areas include occupational health, human resource development interventions, and intervention implementation and translation. By focusing research efforts in this way, best practice approaches can be determined, that are sustainable and contribute to service provider preparedness to cope with challenges of the dementia epidemic.

While Chapter Six described a resilient profile for the dementia care workforce, it did not incorporate views of informal carers. Particularly, yet to be

determined are informal dementia carers' views on what factors contribute to a resilient dementia care workforce. Therefore, Chapter Seven will describe Study 3, which is an investigation of informal dementia carers' perspectives on the future of service delivery in community-based dementia care. Chapter Seven will present qualitative review of informal carers' perspectives in light of formal care workers' perspectives (identified by themes reported in Chapter Five). By comparing both informal dementia carers' and formal care workers' perspectives, an analysis on the alliance between two carer types can be performed. This approach is presented in the following chapter (Chapter Seven), and will aid in the determination of whether or not there is a collaborative approach for the future development of the community-based dementia care workforce.

Chapter 7

Alignment Between Informal Carers and Formal Dementia Care Workers:

Perspectives on Community Service Delivery

(Study 3)

“I would like to have more support ‘cos I am tied to the house. The two support workers are pleasant and helpful, but we want more skills and qualified workers”.

A comment made by a female informal carer.

“There will be more clients and I think probably there has to be more information for us on how to handle the situation and more education for us. Like training, for example”

A comment made by a female formal care worker.

People with dementia become reliant upon others for their care and well-being, and family members often take on the task with little or no understanding of the disease and the changes expected to occur to their family member. The majority of care for people with dementia is given by spouses and family members, who play a major role in patients' day-to-day care (Selwood et al., 2007). Carers are a critical factor in the trajectory of patients' well-being, with the quality of care provided predicting longer duration to institutionalised care (Spijker et al., 2008). However, the enormous public health value of informal care can come at great cost to the carer (Cuijpers, 2005; Zarit & Femia, 2008). Caring for a loved one with dementia can have negative effects on caregivers' mental and physical well-being (Zarit & Femia, 2008). Thus, supporting carers in their role through services that can provide packages to meet their complex and varied needs is paramount.

In Australia, estimates show that it would cost more than \$30.5 billion per year (AE, 2005) to replace all informal dementia carers. In addition, Australia faces a shortage of more than 153,000 paid and unpaid carers for people with dementia by 2029, and of these carers, there will be a shortage of nearly 60,000 paid staff in high care residential aged care facilities and a shortfall of 94,000 unpaid family carers (AE, 2009). The economical contribution of informal carers highlights the importance of sustaining caregivers' capacity to care. Further, good carer self-management and coping predicts longer time to patients' institutionalisation, and fewer hospitalisations (Spijker et al., 2008). Therefore, caregivers play an important role facilitating patient's well-being trajectories and diversion of expenditure otherwise required in dementia care.

The average Australian carer is 48 years of age and female, and she spends up three to four years in her role (ABS, 2008b; StollzNow, 2007). In comparison with the general carer population, carers of people with dementia display higher levels of unmet needs and lower levels of service use, which is considered problematic by Stirling et al. (2010) considering the connections between carer well-being and care recipient disease progression. In Australia, 52% of carers received one or more community care services, while 44% received none (StollzNow, 2007). Four out of five carers in Europe reported a desire for more information on support services and half wanted more information on drug treatments (Georges et al., 2008). When carers experience significant health detriments related to carer burden (i.e., depressive and acute stress symptoms), they can recognise that they would like more help from services (Stirling et al., 2010). Whether or not carers access support during this time may be influenced by their perceptions of support services and delivery of care (i.e., satisfaction with services, approach of workers and health professionals, and suitability of current types of assistance). Carers who have concerns about standards of care and unfamiliar environments may be less likely to access care (i.e., day respite; Robinson et al., 2012). Having more information about carers' perceptions of service delivery may add to further understanding about dementia carers' service use.

Informal carers are a valuable resource in the community. However, for caregivers to remain effective in their roles, further access to tailored support services will need to be addressed. Further, informal carers are considered an important source of the evaluation of the health and aged care system (Lee, Wang, Chiou, & Chang, 2009; Litherland, 2008). Considering the experience and nature

of their caring role, informal carers are a valuable resource for ideas and suggestions on future care packages and services for people with dementia. Feedback from caregivers on service delivery can provide ways for health care professionals to seek better quality of care (Lee et al., 2009). While much research has focused on family carers perspectives of residential care (Harmer & Orrell, 2008; Orrell et al., 2008; Train, Nurock, Kitchen, Manela, & Livingston, 2005), less is known about informal carers' thoughts about service delivery in community settings.

Carer studies in dementia have focused on the burden of the care role (including reaction to diagnosis, psychological, physical and social needs), help seeking and service utilisation behaviours (Brodaty, Thomson, Thompson, & Fine, 2005; Egdel, Bond, Brittain, & Jarvis, 2010; Gibson & Anderson, 2011; Sabat, 2009; Schölzel-Dorenbos, Meeuwssen, & Olde Rikkert, 2010; Stirling et al., 2010; Tobias, Yeh, & Johnson, 2008). Other informal dementia care research has focused on specific characteristics of carers such as rural and remote carers and younger onset carers (Innes, Morgan, & Kostineuk, 2011; Svanberg, Spector, & Stott, 2010). Further, there is a proportion of research dedicated to examining the efficacy of interventions that aim to improve dementia caregiver burden and psychosocial function (Auclair, Epstein, & Mittelman, 2009; Brodaty et al., 2003; Joling et al., 2012; Vernooij-Dassen, Joling, Van Hout, & Mittelman, 2010). Very few published studies have focused on carers thoughts about workforce development and future service provision in the community dementia care setting. One study by Benbow, Tsaroucha, Morgan and Kingston (2011) investigated patients' and carers' views on workforce skill and found five key qualitative themes. These included knowledge about dementia, person centred care,

communication, relationships, support and helping, and people engage in activities. However, they did not investigate carers' views on service delivery or review informal carers' alignment with formal care workers on the future agenda of community dementia care.

Most research that focuses on informal and formal care tends to report findings relating to the amount each type of support is accessed by care recipients (Wimo et al., 2002; Wimo et al., 2011) and the connection between these types of supportive networks (Bakker et al., 2012; Li, Edwards & Morrow-Howell, 2004). However, one qualitative study conducted in Canada, closely investigated the differences between informal and formal carers in the community setting (Ward-Griffin, 2002). Informal and formal carers were found to have completed the same work, however, it was viewed differently. The care work was described with reference to a hierarchy of labour where there was division between informal and formal carers' responsibilities. In particular, informal carers were viewed by both formal and informal carers to be involved with "unskilled" tasks such as personal care, whereas formal carers provided "skilled" tasks, based in experience and knowledge such as emotional support. Ward-Griffin (2002) found that tasks completed by informal carers mirrored formal carers, however, these similarities were not recognised by both carer types. While this research was set in the community, it involved the informal carer of the general elderly (not dementia specific), and formal carers were nurses (not care assistants). While Ward-Griffin (2002) acknowledged the interaction between the care giving tasks and sought to describe the perceptions held by both informal and formal carers about each other, the study is ten years old and does not take into account carers' views on the future of dementia care and population ageing. Thus, the current study reported in

this chapter will investigate, whether or not informal and formal dementia carers in the community have similar views on how to prepare for the future.

When developing and implementing new services, the innovation spread or the coproduction approach has less readily been used with dementia carers that do not access support services (AIHW, 2007; Brodaty et al., 2005). The innovation spread approach (Greenhalgh et al., 2004), suggests that a clear link between the creators of an intervention and those receiving it is needed, in order for successful implementation of that intervention or new service (Lomas, 2011). This relates especially to the likelihood that the intervention will be accepted by the target audience. Thus, investigating carers' and patients' opinions about service delivery is a valid approach. This is particularly the case when there are changes in services delivery and potentials for reform, as is the situation in aged care in Australia.

One rationale for conducting an investigation of informal dementia carers on present and future community-based service delivery, relates to the relatively new approach of including consumers in service development and evaluation (Litherland, 2008). Informal carers and people with dementia are the final target audience, services are aiming to satisfy, by improving service delivery and overall capacity in dementia care. Informal dementia carers may feel disconnected from a service provider, which affects their acceptance of and ability to actively seek support. Considering the informal carers' perspectives on service improvement will allow not only for well-rounded strategies to develop the sector, but also help to deliver a tailored and coproduced message integral to effective service integration and acceptance.

Carers' responsibilities include engagement with a wide range of health services, with carers often co-ordinating care of the person with dementia.

Therefore, carers are regularly involved with range of health professionals and care assistants. Investigating how carers perceive health professionals and care assistants in the dementia sector may offer insights into reasons why a proportion of informal carers do not access services. There may be several barriers for carers to access services, of which establishing a trusting relationship with staff may be central. Stigma of dementia has been found to increase the burden associated with care giving (Werner et al., 2012), and may also form part of a list of barriers informal carers experience when trying to initiate support networks. The current study will examine a small proportion of informal dementia carers to determine the barriers and enablers to seeking formal support from community-based organisations.

The aim of Study 3 reported in this chapter is to highlight the care expectations of informal dementia carers. Several objectives are to investigate the care expectations of informal carers' on; i) present and future needs to be met by support services, ii) satisfaction with services they currently receive, iii) support workers' attitudes, skills and knowledge, and iv) ways to develop the workforce in the future. Another objective of Study 3 is to determine the level of alignment of carers at the coal face of the dementia care sector, in light of preparedness for future demands. This will be determined by comparing the primary analysis of informal carers on the future of community-based service delivery with the qualitative themes identified from data of formal carer workers (from Study 2 – Part A).

Design

A mixed methods design was adopted. Information collected was qualitative and quantitative and analysed independently. An inductive coding technique was used to analyse the qualitative data, whereas scores on quantitative ratings were averaged across the sample. Themes were coded from textual data entered into QSR International's NVivo.8 (2008), computer software designed for qualitative analysis. The inductive coding technique for Study 3 was followed whereby the researcher coded textual data into the three main areas of interest; i) *Carers' needs*, ii) *Organisational change* and iii) *Workforce development*. Firstly all textual data was coded for each participant at "free nodes". Free nodes are the first level of coding of data into a theme. Once all data was coded at free nodes, the researcher then created "tree nodes" to arrange themes into related subcategories based on the areas of interest informed by organisational and clinical psychological theories. Tree nodes allow for themes to be organised into a hierarchy such as branches on a family tree (see Figure 4).

Participants

Thirty-six informal dementia carers were recruited from Tasmania, Australia. Informal dementia carers participated in an interactive workshop titled "What are your support needs? Exploring the match between support needs and support services". This was held at the first national Carers Conference in March 2010 titled "Carers First: Staying out in front - now and into the future" conducted by the Commonwealth Respite and Carelink Centre, in Hobart, Tasmania.

Procedure

Informal carers enrolled in the Commonwealth Respite and Carelink Centres' database in Tasmania were invited to attend the first national Carers Conference in March 2010. Prior to attending the conference the carers selected workshops they wanted to participate in. One workshop included "What are your support needs?" co-presented by the PhD Candidate and her Primary Supervisor and Senior Lecture, Dr Jenn Scott. The aim of the workshop was to provide a place for carers to express their opinions about the services they received and their current unmet needs. Four discussion questions were asked of the group:

- i) What are family carers' unmet needs for support in their roles?
- ii) What are the barriers to meeting their needs?
- iii) What are carers' views on worker attitudes, skills and knowledge?
- iv) What are carers' views of what would improve services?

After the discussion workshop, participants were invited to complete a two page handout, where they could write down their answers to the discussion questions.

Demographic information was collected such as age, sex, relationship to the care recipient, length of years caring and whether or not the carer resided with the care recipient. In addition, participants were asked to rate their extent of overall satisfaction with the support they receive on a seven point Likert scale (0 = not satisfied, 6 = extremely satisfied), and their confidence in talking to a support worker about the tasks they complete on a seven point Likert scale (0 = not confident, 6 = extremely confident; See Appendix E).

The researcher (PhD candidate) explained to the participants that the information collected would form part of a brief report to Commonwealth Respite and Carelink Centre South Tasmania, to enable service improvement, and also

form part of the PhD Candidate's project investigating dementia care services. No identifying information was collected and participants were reassured of their rights to not hand in their written answers. Participants submitted their handouts to a conference attendant, who then passed the forms to the workshop presenters.

Results

The majority of informal carers were over 65 years, female and cared for their husbands. Nearly a quarter of carers were males, caring for their wives. The average amount of time informal carers had been in their role was for seven years ($\bar{x} = 7.3$, $SD = 7.8$). Most carers were moderately to highly satisfied with the support they received from community care services (scored equal to 3 or 4 out of 6, $N = 13$; scored 5 or 6 out of 6, $N = 10$) and a minority were dissatisfied (scored less than 2 out of 6, $N = 3$). The majority of informal carers were highly confident they could talk to support workers about the tasks they completed (scored a 5 or 6 out of 6, $N=19$; scored less than or equal to 3 or 4 out of 6, $N = 9$). Some informal carers did not rate their satisfaction ($N = 5$) or confidence ($N = 7$) and a small proportion had not accessed support services ($N = 3$). Table 14 shows the demographic characteristics of all informal dementia carers. For details on demographic characteristics of formal paid dementia carers see Study 2 – Part A.

Table 14

Demographic Characteristics of Informal Dementia Carers

Informal carer	N	%
Sex		
Male	8	22.2
Female	27	75.0
No information	1	2.8
Age		
≤ 34	1	2.8
35-49	3	8.3
50-64	9	25.0
65-70	20	55.6
≥ 70	3	8.3
Relationship		
Wife	14	38.9
Husband	9	25.0
Mother	6	16.7
Father	1	2.8
Brother	2	5.6
Other relative	3	8.3
Multiple caring role	3	8.3
Reside with PWD		
Yes	35	97.2
No	1	2.8
Length of caring (years)		
1	1	2.8
2	9	25.0
3	5	13.9
4	1	2.8
5	5	13.9
7	1	2.8
8	3	8.3
9	1	2.8
10	6	16.7
15	1	2.8
18	1	2.8
28*	1	2.8
40*	1	2.8

*Note.**Multiple caring role, PWD = Person with dementia

Qualitative themes

Information collected from the 36 handouts was typed into word documents that were imported into QSR Nvivo.8 software and coded for themes. Three super-ordinate themes were identified; i) *Carers needs* ii) *Organisational change*, and iii) *Workforce development*. In total, 135 themes were identified in the data. Thirteen constituent themes were found within the main super-ordinate themes (see Figure 4). Inter-coder reliability was undertaken using a secondary coder, a PhD Candidate, who had no prior involvement in the investigation, but had the same level of experience with coding and use of the QSR Nvivo.8 program as the primary researcher. The secondary coder in Study 3 was the same secondary coder as Study 2 – Part A. The inter-coder reliability test revealed minor differences with an average kappa coefficient of 0.94 and an agreement average of 99.12 %. These differences were associated with the extent that coders included space around the words in the coding sentence strip.

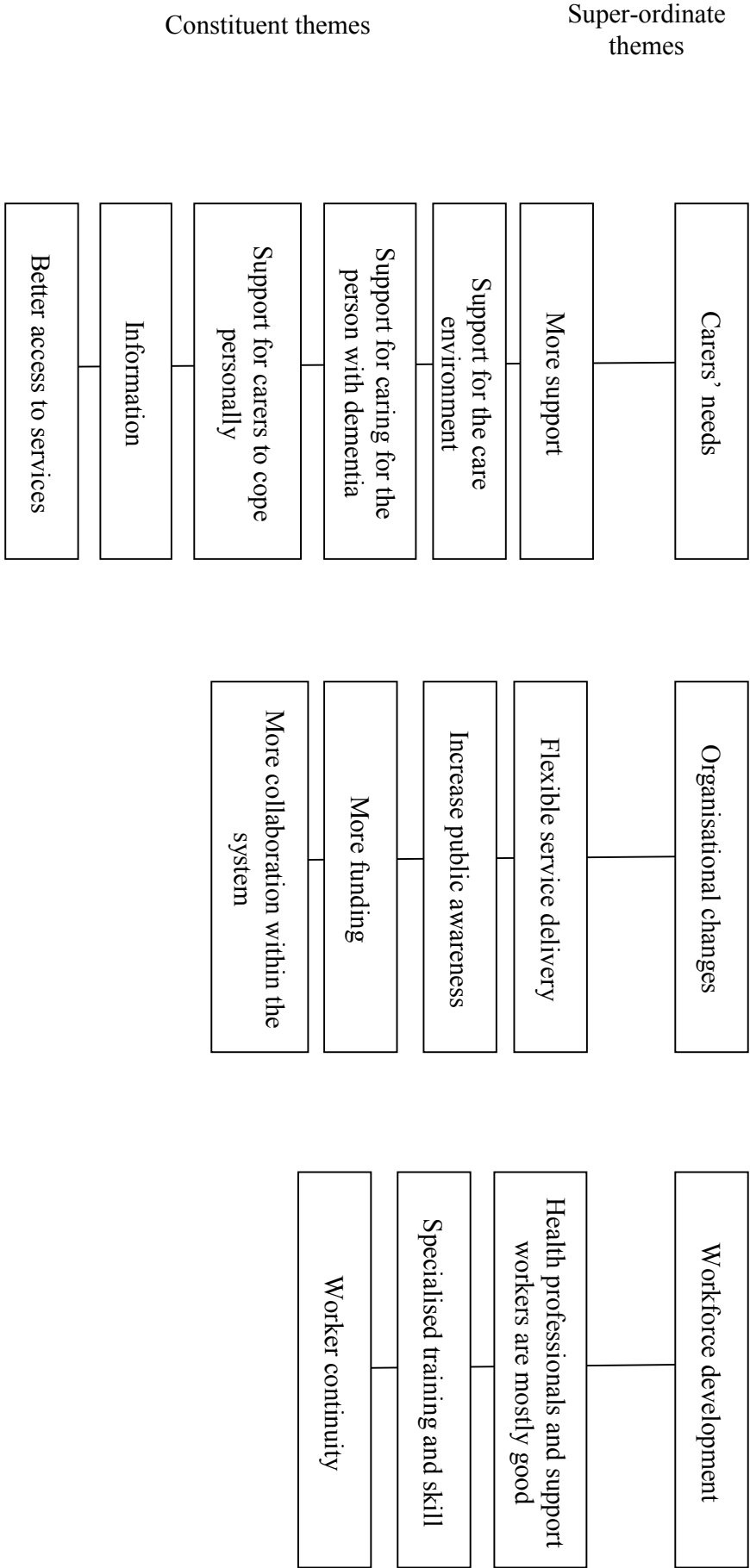


Figure 4. Identified themes for informal carers of people with dementia.

Carers' needs super-ordinate theme

The *carers' needs* super-ordinate theme summarised carers' comments about the areas where they felt they needed support within their caring role. This included a range of needs not only for the carers themselves, but also for the person with dementia. Most carers made reference to wanting *more support*. For example:

I would like to have more support to enable me to do physical exercise to keep fit as well as present support I have to keep up my fluency in a foreign language. Garden help every three months is too long [to wait], (Informal Carer 27).

Many carers reported a range of needs, wanting *support for the care environment* that included assistance with home maintenance, cleaning, and other tasks associated with the living environment. Carers reported wanting assistance with tasks they might struggle to do themselves, which might have traditionally fallen to the care recipient's family role, before they were diagnosed with dementia. One carer with general health problems who cared for her husband stated "I require a man to help me do some gardening and general clean and tidy up. I have had both hips operated on and find it difficult to manage" (Informal Carer 11). Another carer reported wanting improved cleaning services and highlighted a current problem stating "[there are] restriction[s] for the services such as cleaner can't lift [a] chair, they only do vacuuming" (Informal Carer 18). This quote demonstrates a desire by carers for cleaning and home maintenance services to be more flexible in the way they provide support.

Specific support for the person with dementia was found to be part of the *carers' needs* theme. Carers wanted help with providing companionship and

social interaction for the person with dementia, as well as more flexible respite options. One carer stated she wanted “more visitors for mum, companionship, I can’t do it all... others to take her shopping, for a drive out for meals, coffee”

(Informal Carer 8). The same carer commented about respite saying she wanted:

More flexible respite (i.e., uniform days needed rather than only full weeks-weekly, fortnightly, etc.), more opportunity for the same place respite, so not always going into strange environments, easy weekend respite, so life can continue for me and my husband and family.

Another carer commented it “would be brilliant to be able to go away for a day/night when asked without too much re-planning, back-up night support”

(Informal Carer 33). While another requested in-home respite and said “I would like short term overnight respite to be provided in our home when I go away. I don’t think it is appropriate for a 95 year old to go into respite for the first time at this age” (Informal Carer 10). While carers showed desire for practical support, it was often focused on *support for caring for the person with dementia*. Carers wanted this type of support to be tailored to their needs and less restricted by the package of care. This lack of flexibility at times seemed to act as barrier for carers to engage with services (i.e., respite).

The *carers’ needs* theme also included carers commonly reported a need for support for themselves in their caring role. This constituent theme focused on *support for carers to cope personally*. One carer highlighted this need and stated she wanted the “support provider to provide more support to carers and not focus entirely on recipient... [and help with] managing depression, mindfulness, massage, exercise, yoga, positive optimal support . Support for other member of family, e.g., my daughter” (Informal Carer 13). This quote demonstrates the need

carers have for psychologically focused support to deal with the consequences of the caring task. It also includes the need for this type of support to extend to other family members such as children. Another carer highlighted the effects of the caring role on psychological well-being and stated “as a carer there are times when I need support for my emotions and mood to cope” (Informal Carer 7). One carer identified with the *support for carers to cope personally* and described having “a need for psychological guidance in learning the new role of the carer with the old role of the spouse... a need for self-assessment program, how to improve my performance as a carer” (Informal Carer 4). This quote demonstrates a need for ongoing support where not only the carers’ health and well-being is managed, but also their ability to complete care tasks and adapt to their role. In some cases personal support was expressed as a need for assertiveness building as one carer commented about this situation as barrier to accessing support and suggested she should “not be put off by someone not listening to us, when we are put off when we ask again” (Informal Carer 8). Another carer mentioned their need to talk with someone, asking for “a break for me to just talk to someone about problems” (Informal Carer 21). While the *support for carer to cope personally* theme was generally seen as a need by carers, some carers also viewed their stress as a barrier to accessing additional support services, and also wanted assistance for their family members.

The *carers’ needs* theme was also found to include a need for *information*, with most carers wanting information about the caring role. One carer answered the question, what are family carers unmet needs by stating “[information about the] role of carer” (Informal Carer 2). Another carer reported “I am not sure of the help... available” (Informal Carer 18). While another carer made a similar

comment and stated “as yet I don’t have all... the information [about what support] they will give me” (Informal Carer 5). Information about services available for carers was one unmet need identified. Some carers thought that a lack of information about services acted as a barrier for them to access support. For example, one carer commented “I need to know about other services available and what support they provide” (Informal Carer 15). Carers also talked about wanting support in terms of *information* about transition in care environments, and one carer said they wanted “advice and help concerning transition between home and aged home, when is it best to look after my own well-being and decide to seek permanent care in an aged care” (Informal Carer 8). Informational needs extended from the carers themselves, to their extended family and other community members. One carer illustrated this by saying they wanted “more support from family members, they need educating!” (Informal Carer 10).

Better access to services also contributed to the *carers’ need* super-ordinate theme. The *better access to services* constituent theme was representative of carers wanting an improved introduction to services. For example, one carer said “[it was] slow to get into system, once I was in, it gets better as time goes by” (Informal Carer 16). This quote demonstrates the difficulties carers find with accessing services during the beginning stages of their care roles. This theme also included comments about the distribution of services, such as issues relating to finances that impact on carers accessing services, as well as additional support needed to access respite options. One carer wanted better distribution of services and stated services should “abolish geographical placements of [the care] package” (Informal Carer 13). When asked what the barriers to meeting her needs were, one carer commented “finances of course” (Informal Carer 8), and another

carer stated, “being able to access a centre without paying” (Informal Carer 34). Highlighting the difficulties of taking up respite options, one carer reported “when respite is required I find it very hard as the rest homes do not give proper care and I find that [the care recipient] is very unhappy being away” (Informal Carer 11). By using the term “proper care” the carer is eluding to standards in quality of care, therefore the *better access to services* theme extends to include concerns in access to quality care and how carers perceive the environment in which their care recipient will be placed. In addition, some carers reported not needing assistance or not currently receiving support. For example, some carers stated “not needing any [support] at present” (Informal Carer 7), “have not needed support so far but it won’t be long” (Informal Carer 9), and “have not applied for support as yet” (Informal Carer 24). Overall, the *carers’ needs* theme showed a range of unmet support needs for carers to perform their roles.

Organisational changes super-ordinate theme

The *organisational changes* theme describes the desires of carers for there to be improvements in the way service providers operate and deliver support. Despite being generally satisfied, with services carers reported wanting more types of support in the future. In particular, one carer suggested services “provide outreach...” (Informal Carer 13) to better accommodate for clients in regional areas. Carers recognised that the service providers needed *more funding* to deliver support. When asked “what are the barriers to meeting your needs?” one carer responded “funding for support service” (Informal Carer 1). In addition, carers wanted improved flexibility in services, demonstrated by a quote from one carer as they wanted “support providers policies and guidelines to be more flexible to individual needs (i.e., care plan/cleaning plan drawn up to suit each carer)”

(Informal Carer 13). This comment not only highlights carers' desire for *flexible service delivery*, but further illustrates the strong desire for practical support services to be tailored to individual needs, where assessment and planning processes occur. Carers also expressed wanting flexibility in the length that a service was provided. When asked "What do you think would improve services?" one carer stated "... more time allowed for respite both for clients and carer" (Informal Carer 3). *Organisational changes* suggested by carers were focused on being able to provide better care to the person with dementia.

The need to *increase public awareness* was identified by carers as an important way to improve service delivery in the future. One carer suggested to "spread the word" (Informal Carer 14) about dementia within the community while another suggested to "make more use of the media" (Informal Carer 5) as a way to resolve lack of awareness and understanding about the disease. The lack of understanding was seen by carers as a barrier for people to access services. One carer commented "the lack of community understanding of what carers do and why they do it" (Informal Carer 10). This comment alludes to the idea that services may not be aware of the many ways dementia is experienced by individuals in the community, and what this may mean for carers and families support needs. *Increasing public awareness* not only included raising the community's understanding about the disease, but also raising the profile of the services within funding and policy spheres. One carer stated that "... sending out the message to both the governments and public that these services are available and so necessary" (Informal Carer 5) would help to increase awareness. In the *organisational changes* theme, carers identified that it was the responsibility of support services to *increase public awareness* about the disease, causes of

dementia and symptoms, and how it affects carers, as well as the types of services available to carers, family members and people with dementia.

The *organisational changes* super-ordinate theme included carers' desire to have *more collaboration in the system*. In particular, one carer wanted "more communication" (Informal Carer 30) as a way to improve services. "More co-ordinated care options and collaboration" (Informal Carer 28) were other ways of improving services expressed by one carer. This was also supported by another carer who stated "doctors working better with support workers" (Informal Carer 6) would improve services. This also extended to better service delivery from administration side of services, and one carer stated "better service from the office" (Informal Carer 8) while another stated "non-judgemental support from administration... service provider policies and guidelines" (Informal Carer 13) would improve service delivery. One carer identified "the system itself" (Informal Carer 16) as a barrier to accessing support services. While carers requested flexibility in service delivery they also wished for better collaboration between current services and within the system of care. Carers also expected that people in administrative roles need a better understanding about dementia and carers' experience and subsequent needs.

Workforce development super-ordinate theme

The *workforce development* theme included a reflection of carers' thoughts about health professionals and support workers abilities, skills and knowledge to perform their job roles. Overall, this super-ordinate theme showed a general level of satisfaction with professionals, however, significant suggestions for improvement were made. One carers' comment described this in relation to support workers and stated workers' "attitude, skills and knowledge have been

quite satisfactory, easy to contact, and more importantly support staff listen to concerns and act on them. My brother has a good rapport with his home help cleaner which is advantageous” (Informal Carer 36). Most carers agreed that support workers vary in their attitudes, skills and knowledge, but were “mostly good” as they found their caring helpful and they appreciated their support. One carer stated support workers “vary, most [were] very good” (Informal Carer 11), while another stated they were “usually very good” (Informal Carer 3). Carers’ comments generally related to the level of care they received from the support worker or health professional. For example, one carer stated “I appreciate the respite care I’m receiving” (Informal Carer 15). Here the carer places the emphasis on the service and not the worker. Most carers’ comments were about the care role and quality of the service rather than the relationship they had with the support workers. Another carer highlighted this and stated “most of the support workers are great and help to make things easier as my caring is... all day every day” (Informal Carer 14).

One carers’ comment suggested that it takes time for support workers to adjust to their role and stated “[workers’ attitudes, skills and knowledge was] bad to start with, once established needs, [the recipient is] being attended to [and] it’s very good” (Informal Carer 26). It appears that early on in the care relationship, support workers were learning how to provide support specific to the care recipient, which generally developed and improved over time. Carers identified why support workers vary. For example:

Support workers attitudes, skills and knowledge derive from the service providers. From time to time, support workers attend [to the] code of

conduct, non-biased judgements, to ask the questions at the right time [and] to earn trust from carers and [the] recipient (Informal Carer 13).

While this quote shows general satisfaction and acknowledgement of an humanitarian and ethical approach to care, it also shows that workers' skills in this area can vary. According to informal carers this care approach appears to originate from the organisational culture experienced by workers.

Carers who expressed dissatisfaction with health workers generally reported a negative experience with a health professional or worker. An example of this was when one carer stated that her "local GPs [General Practitioners] should be better informed about dementia. My husband's GP treated my concerns as a joke" (Informal Carer 1). Other complaints included that support workers were "not staying for time allotted" (Informal Carer 30) and that "others won't allow patient to still 'do' what he can for himself, [support workers] seem to want to get the visit over and move on" (Informal Carer 33). While most carers were satisfied with workers, they also acknowledged that their skills varied and improvements were needed.

Specialised training and skill was a *workforce development* need. Many carers expressed that a way to improve services was to advance training within the workforce delivering the care and support services. While carers wanted professionals to be "better informed about dementia" (Informal Carer 1) they also wanted workers to be knowledgeable in the available support services. One carer stated "...doctors and hospitals [need] to have documentation, pertaining to different illnesses with a list of what services [that] may be worth approaching" (Informal Carer 26). Carers agreed that training for workers should extend to include "cultural diversities and disabilities" (Informal Carer 13). Carers also

wanted specialised assistance which they recognised needed “a definite knowledge of what is required [and] the skill and education of methods to use” (Informal Carer 2). One carer stated “they have all done their very best to offer their services but have been unable to persuade my mother to accept them (i.e., showering)” (Informal Carer 17). This quote demonstrates the lack of specialised skills of workers to deliver support services (such as personal care) to people with dementia, despite their commitment and determination. Informal carers reported one of the outcomes of lack of training was that “[workers] do not have enough training as to take over [their] role[s] with [their] own initiative” (Informal Carer 12).

Worker continuity was identified by carers as a necessity for *workforce development*. One carer commented “the office staff contact are different every time they ring up to change the time, there should be continuity” (Informal Carer 23). Another carer stated “because of [my] brother’s blindness he needs continuity” (Informal Carer 33). This theme extended to include shortages in staff which lead to inconsistency in care delivery. For example, one carer stated a “shortage of home help personnel leads to service[s] being cancelled regularly” (Informal Carer 23). Carers spoke of a “lack of health professionals” (Informal Carer 14) to deliver services as a barrier to having needs met, which may be particular for the regional carer experience. While the quality of support workers and health professionals remains important to carers, so too was the continuity of the services that these workers provide.

Alignment between informal carers and formal carer workers

Firstly, the demographic characteristics of each carer type are compared. Secondly, themes identified by both groups of carers are reviewed according to

practical caring roles, coping with care roles, the care relationship, as well as issues related to the workforce and service delivery.

Some similarities were present regarding the demographic characteristics of informal and formal dementia carers. The majority of carers were female (Informal Carers, $N = 27$; Formal Care Workers, $N = 22$) and over 50 years of age (IC, $N = 32$; FCW, $N = 14$). Similarities were also found between the two carer types regarding their roles. The majority of informal carers had been in their care roles for an average of seven years ($SD = 7.8$) while the majority of formal paid care workers had been employed on average for six years ($SD = 4.3$) in the sector. While most informal carers resided with the care recipient ($N = 35$), the majority of formal paid care workers were employed on a casual basis ($N = 16$) and worked on average 27 hours per week.

Practical caring roles

Paid dementia care workers have the option to work part-time or, on a casual basis where they can control the number of hours they work. Workers also have the option to cease employment and their multiple caring roles. Informal carers do not have such choices. Despite these differences, both carer types discussed similar practical aspects of the caring role and highlighted several unmet needs in their roles. Informal and formal carers wanted more information about dementia. In particular, both acknowledged that more awareness about dementia in the community is needed, and that increasing awareness would make their roles easier. Informal and formal carers reported problems with isolation. Informal carers felt “tied to the house”, while formal carers felt “working alone was a downside”. Other convergent findings related to the need for more allotted time to spend with people with dementia, with a focus not just on performing practical

tasks, but also tasks that promote social support and interaction. While both types of carers reflected similar needs, their roles differed in intensity by the number of caring hours with the same care recipient and familial relationship ties. This was found to contribute a difference in coping needs.

Coping with care roles

While informal carers highlighted a need for individual support to help them cope in their care roles, such as access to counselling and psychological assessment and treatment, formal carer workers reported no such need. Instead, formal paid carers reported a need for reflective work practices where they could attend regular meetings with co-workers to discuss in a professional manner the clients they were caring for and seek advice when needed. This was seen by workers as an opportunity to “debrief” and cope with the demands of the caring role and was described as a part of occupational communion in Study 2 – Part A. While formal carers seek peer social interaction to manage their isolating work, informal carers want more specialised psychological assistance.

In addition to social and psychological support, both carer types identified a need for more financial assistance and better access to resources. While informal carers wanted services provided with no cost and better respite options, formal carers wanted better remuneration and improvements in financial support to perform job duties (e.g., access to resources for clients such as electronic lift chairs and financial support to maintain transport). All carers acknowledged that financial support would help them to cope better with their roles, and would reduce barriers to quality care.

Care relationship

Formal paid dementia carers mentioned many practical aspects of their caring role. They also highlighted a significant interpersonal aspect of their work (occupational communion). Formal carers appear to be strongly connected to their work due to their own personal need for interaction with others. A similar concept was not mentioned by informal carers, which creates an interesting dynamic. In particular, informal carers' perspectives emphasised the service and not the worker. Most informal carers commented about the care role and quality of the service rather than the relationship they had with the formal care workers. On one side of the dyadic interaction the formal care worker is motivated to help and deliver care to the person with dementia and their informal carer. This may be due to the rewards they reap from building a trusting relationship and engaging in regular social interaction. Conversely, the informal carer and person with dementia are focused on having their needs met (by accessing a quality service) so they are able to get on with their lives as usual.

For the majority, carers' views on each other are positive, however, for a minority of carers there are some concerns. The positive experiences of informal carers show they "were appreciative of workers", consider them "very helpful" and suggest they "need acknowledgement for their good work". Informal carers said that formal care workers "use kind speech" are "caring and considerate", and that "they listen and act". Care workers held a shared view and reported that "listening", "being respectful and empathic" helped the professional caring relationship. Care workers' positive experiences of people with dementia and their informal carers included that they "they enjoyed being with their clients" and that offering support created positive feelings.

Informal carers and formal care workers both acknowledged the challenges associated with starting the relationship with the person with dementia. In particular, workers identified that engaging the person with dementia was difficult, and informal carers reported that “workers are good once they are established”. Informal carers had some negative views of formal care workers’ attitudes, skills and knowledge, for example “workers need to care more” and “lack understanding about disability (vision impairment)”. Formal care workers mentioned that “conflict with carers and family members”, “unrealistic demands” of clients and “unsupportive and critical families” all make the relationship a challenge. Carers’ perceived gaps in workers skills that resulted in an agreed need for workforce development.

Workforce

Informal and formal carers both raised concerns about workforce issues that are distinctive to the regional situation. While informal carers showed concern for low numbers of specialised health professionals in their area, formal carer workers recognised the need for more specialised training and higher levels of qualifications to be held by workers in dementia care in the future. Worker continuity was also a concern expressed by both carer types, with informal carers recognising how staff shortages can influence the continuity of care for the person with dementia. Formal care workers highlighted how changes in the clients they care for can be difficult to manage, particularly in light of the loss of relationship and trust that was established over time. Informal carers consistently commented that workers need training and knowledge of dementia, while formal care workers recognised that knowledge of dementia helps the caring role.

Services

Informal carers and formal care workers both mentioned problems, and challenges with current community-based dementia support services and ideas to improve these services for the future. Ideas did not diverge greatly for informal and formal carers and there was commonality across themes. Informal carers suggested ways to improve services in dementia care were to operate under a “case management approach”, as “enhanced communication within services”, and “more flexibility” for individuals needs were required. Workers reported similar themes suggesting co-ordination of dementia care as a challenge for the future.

Further review of themes found an alignment between informal carers and formal care workers on their reports for more funding support for resources and community care, a need for professional standards, and concerns about the organisational system in which community dementia care operates. In particular, carers agreed that more services were needed to focus on the social participation of people with dementia. Informal carers requested “companionship” for care recipients, and formal carers acknowledged the importance of making time to “have a cup of tea” to provide social interaction. Community excursions and more social activities designed for people with dementia were desired by carers. Both care types recognised that improvements in funding would assist problems of access to resources for people with dementia and their carers.

Discussion

Informal dementia carers are generally satisfied with the support services they receive, however, they believe that much can be done to improve present and future service delivery. They generally find it easy to communicate with people providing care to the care recipient, such as formal care workers. Informal carers thought workers' attitudes, skills and knowledge varied, but were "mostly fine". Carers who were dissatisfied with services generally described a particularly negative event that occurred with a health professional or worker. Themes identified by carers showed unmet care needs for their support role and a desire for organisational changes, and workforce development to meet carers' needs in the future. Informal carers' and formal care workers' care expectations and perceptions on the future agenda of community-based dementia care were found to align, with slight exception for themes about the care relationship.

While the findings from the current study reported in this chapter offer a shared view held by informal and formal carers, there were some limitations of the study that need to be considered. Limitations of the current study included the depth of the information offered by carers. While written comments on handouts provided good practical information about informal carers' perspectives, descriptive detail and qualitative expression were less available. Informal carers tended to have quite short and to the point answers to questions in the handout. Recording the workshop discussion for evaluation purposes may have assisted with the provision of more detailed responses from carers. This may have implications for the level of understanding of informal carers' support needs and thoughts about service delivery provided in the current study reported in this chapter. However, this approach has been adopted by previous studies (Benbow et al., 2011) and is therefore consistent

with literature in the field. The comparison between informal and formal carers qualitative themes may be influenced by the different data collection methods applied, despite similar data analysis procedures. Dementia carers were all from Tasmania, therefore representing a specific island perspective, and potentially reducing the generalisability of findings. Informal carers self-referred to the current study, therefore minimising the likelihood of recruiting carers that were experiencing depressive symptoms or not engaged with a community service provider. Despite this limitation, the current study did recruit three informal carers who had not yet accessed services, and may have been attending the conference workshop to find out more information about available support.

Similar to previous findings, the current study consisted of informal carers who were mostly female and caring for a spouse (AIHW, 2007; Selwood et al., 2007). Unlike national data, the current study found carers were mostly 65 years or older, while the average age of the general Australian carer is 48 years. This may reflect a difference between dementia carers and general carers, as well as the trend for a higher proportion of older adults retiring in regional and coastal areas, which can also be found in the island State of Tasmania (ABS, 2011; Henderson & Caplan, 2008). In addition, informal carers in the current study reported in this chapter, spent longer time caring for their care recipient, three to four years more than other national studies (StollzNow, 2007; USAA, 2009). This can be explained as the Study 3 was representative of an older sample, and therefore, more likely to have been caring for longer. However, the characteristics of the current sample did not appear to influence the similarities between the findings of Study 3 to previous research on carers needs.

Information and access issues were raised by informal dementia carers, similar to other international studies (Georges et al., 2008; USAA, 2011). Informal carers wanted support and care to be tailored to their needs so that care plans were flexible. Some informal carers showed a disconnection with service providers and problems with accessing services included not enough knowledge about what was available, which was viewed as a barrier to meeting carers' needs. Thus, access to more information about the services available and better community understanding about dementia was requested by carers. By improving community understanding about dementia (in particular carers' needs and available services) existing social and community networks may be able to inform and prepare carers about the available supports. The lack of community understanding about dementia may be related to the stigma of the disease.

Stigma of dementia has been found to increase the burden of the disease on carers (Werner et al., 2012). Therefore, accessing services may be more of a challenge for dementia carers in comparison to other types of carers, due to the stigma and lack of public awareness about the disease. Further, stigma has been found to extend to the professional setting where physicians often delay diagnosis of dementia (Kaduszkiewicz et al., 2009; WHO & ADI, 2012). Lack of public awareness not only contributes to carer disconnection with services, but was also found to be in the top of ten factors viewed as a challenge to meeting America's National Alzheimer's Plan (USAA, 2011). Dementia often remains in the shadows and warning signs, misplaced anxieties and misconceptions must be overcome so that the hardship of the disease is not exacerbated by stigma and lack of knowledge (USAA, 2011).

Informal dementia carers felt it was the responsibility of support service organisations to increase public awareness, where carers wanted more use of the media to educate the community. Acknowledging carers' ideas to overcome challenges and the adoption of coproduction principles have been used previously in the United Kingdom where the community was included to create projects and services (Szebeko & Tan, 2010). This approach is also advocated by Downs and Bowers (2008) as a core part of service development and evaluation in a critique of excellence in dementia care, and may be appropriate in the Australian setting. Further, following an innovation spread approach (Greenhalgh et al., 2004) to service delivery in dementia care may reduce the disconnection between carers and support services. Involving carers and the community in service development and implementation, such as innovative public awareness campaigns may also improve dementia carers' use of services.

Dementia carers residing in inner-regional or regional areas may experience a heightened sense of disconnection from services that reflects their geographic and social isolation. The health literacy of Tasmanians is one of the poorest in the nation with around two thirds (63%) assessed as having insufficient health literacy skills compared to 40% of people in other Australian States (ABS, 2000). This may account for a small proportion of the current sample not accessing services. Informal dementia carers reported wanting more flexible service delivery, which included the provision of outreach services. Problems were highlighted with worker continuity, where dementia carers acknowledged that low worker numbers and a lack of qualified health professionals contributed to inconsistency in care delivery. These findings are confirmed by literature on shortages of health professionals, found to be most prominent in regional and rural areas (ACG, 2007) which are

often associated with problems with in multi-disciplinary competency (Booth et al., 2008). Informal dementia carers from areas like Tasmania, where the population is dispersed, may face additional challenges unique to their geographic location such as inconsistency in care, lack of information about services and poor health literacy that affect their likelihood to access support services.

While carers requested flexibility in service delivery they also wished for better collaboration between current services and within the system of care. Adopting a multi-disciplinary approach may improve collaboration across a wide range of health services for people with dementia and their carers. Further, following a multi-disciplinary approach may advance developments in the field, similarly to the past ten years of psycho-oncology expected to continue to develop further in the translational arena (Cao et al., 2011).

Carers in the current study acknowledged that workers were “mostly good”, but also highlighted a workforce development need for training and education specific to dementia. Developments in public policy in some nations (e.g., Australia's National Framework for Action on Dementia, 2006; Canada's Rising Tide, 2010; England's National Dementia Strategy, 2009) across the globe support this finding, as dementia plans suggest improvements in dementia knowledge and skills are needed for workforce development. While there is a consensus that the dementia care workforce requires specialised training and education in dementia, greater understanding of ethical delivery of services in particular regard to culturally diverse populations was expressed by informal carers in the current study and supported by previous findings (Doyle et al., 2009). Additional research may help establish in more detail the training needs of workers in dementia care to help

informal carers feel the support they receive meets their needs and is both consistent and of quality.

Overall, the qualitative themes identified by informal and formal dementia carers align to show carers want improvements in access to information and support, workforce training and service delivery in the community setting. In addition, both carer types engaged in similar practical caring tasks despite being a relative or in a paid role, which was supported by findings from a community-based study on nurses caring for the elderly by Ward-Griffin (2002). One exception to the pattern of strong alignment was found regarding the care relationship, where workers appeared to be motivated by a social need to interact with people. Whereas there was an absence of similar features mentioned by informal carers. Previous research (Benbow et al., 2011) found that relationships with staff were important for informal dementia carers and their care recipients. In particular, carers appreciated staff who “went the extra mile” (p. 199) and they perceived these staff as more caring and committed when they performed tasks outside their official duties. An interesting dynamic was found in the current study for the care relationship where the connectedness to the caring partnership from the perspective of the formal care worker in some ways appeared to be unreciprocated, however, this was not supported by previous research. In contrast, Benbow et al. (2011) reported a similar situation, except for people with dementia and their carers who stated that, “we wish for consistency in our care plan, where we can build up trust, maybe make a friendship with our care-workers” (p. 199). Despite the preliminary findings of both the current study and those of Benbow et al. (2011), further research into the care relationship is required to advance understanding in the dynamics that may contribute to situations of conflict that make for additional

strain on the caring role. This may assist workers and informal carers to deal more effectively with their already challenging situations.

Community care services operate within an organisational system that is often ruled by funding requirements and service regulations. This may help explain why there are problems associated with lack of time per client and accessibility of resources. The regulations and service requirements often stipulated by funding appear to have created a shift towards care delivery that is focused on the physical health needs more than the social and emotional care needs, where a lack of concentration on the overall well-being of patients and carers occurs (King, 2007). In order to meet carers and people with dementias' needs, support and care organisations need to work out how they can be flexible in their service delivery while still meeting funding requirements. If problems exist where this is not possible, lobby groups must provide representation for the services and their clients for system change that facilitates a focus on clients' holistic care needs. For example, in Australia there is an alliance between 28 aged care organisations seeking government and policy reform within the aged and health care sector (Age Well Campaign, 2012). Ensuring dementia is high on the agenda of similar reforms internationally is vital.

Further research in capacity building in dementia care will help ensure support services are able to meet carers' needs. This agenda is paramount considering the relationship between carers' well-being, patient disease progression and hospitalisation, as well as the subsequent economic savings resilient carers provide society. Informal dementia carers who utilise support services have a preference for tailored care where they want better qualified workers to meet their wide ranging needs throughout the disease trajectory. Formal care workers

recognise the future agenda involves workforce development. While carers at the coal face agree on ways to improve service provision, the views of managers concerned with service delivery and implementation remain relatively unknown. An extension of the current study may involve an investigation of the organisational perspective provided by senior management, co-ordinators and supervisors, to determine whether multi-level agreement occurs. For a sector where collaboration and multi-disciplinary co-ordination are at best in preliminary stages (Fortinsky, 2001), a multi-level research agenda is likely to be a challenge. However, future research into service delivery and organisational changes associated with preparedness for the ageing population must be viewed from all levels (e.g., informal and formal carer, care recipient and service provider), if only to enable a coproduced message that is likely to contribute to implementation success.

Chapter Seven provided a description of the connections between studies reported in this thesis (e.g., thematic results from Study 2 – Part A and Study 3), with a particular focus on informal and formal dementia carers. A full integration of the findings across the series of studies in the thesis is presented next, in Chapter Eight. The strengths of the thesis will be acknowledged in this next section. Implications for future research, translation of research into practice and policy will also be discussed in Chapter Eight. Another section of the next chapter will list several recommendations that provide suggestions that are essential for capacity building strategies and resilience for the dementia care workforce. In the final section, Chapter Eight will present the conclusions of the thesis.

Chapter 8

Overall Discussion: Research and Translation Implications

“We did it with cancer in the 70s. With HIV in the 80s and 90s. We fought the stigma, stepped up to the challenge and made massive in-roads into fighting these killers. Now we’ve got to do the same with dementia”.

A comment made by David Cameron, Prime Minister of England (2012, para. 16).

The aim of the thesis was to broaden the understanding of capacity building for dementia care. An objective of the research was to investigate and provide suggestions for capacity building approaches to enhance the dementia care workforce, in order to overcome human resource problems associated with the dementia epidemic. In the thesis, a combination of approaches was presented to investigate capacity building for dementia care and provided consensus for further development of research in the area. A novel approach was presented applying organisational, clinical and social psychology theoretical frameworks to capacity building for dementia care. In Chapter Eight, an integration of results from the investigation is presented with a particular focus on workforce training, occupational communion, dementia specific job demands and resources and workforce resilience. The alignment of care expectations for informal and formal carers is also presented, followed by suggestions for capacity building strategies. The strengths of the research are also discussed. The research and translational/applied implications are discussed with relevance for policy implementation. In addition, a list of recommendations is presented and intended to inform future research, as well as service providers and policy makers on approaches to overcome issues of recruitment and retention in dementia care. The recommendations also focus on development and strengthening strategies for the workforce.

The thesis collectively examined ways to improve service delivery for people with dementia, in order to provide recommendations that contribute to innovative strategies for capacity building in dementia care. Several gaps in the literature were identified. There was an overall lack of understanding about capacity building in broad sense, and most literature focused on the acquisition of dementia

knowledge and care skills. Little focus was on employee stress and coping, and the studies that had reviewed this area often used unreliable measures to assess worker adjustment to high job demands. Further, most research on dementia care workforce issues were focused on the residential setting, with less research focused on the community-based arena. It was identified that there was a lack of systematic evaluation of the effectiveness of dementia training interventions with a focus on worker and organisational outcomes. In addition, little research had focused on the meaning of social interactions for the community-based dementia care workforce. Research on service development that included the views of informal dementia carers' on service delivery was identified as relatively new. The thesis contributes several key findings that add to knowledge in the aforementioned gaps in the literature about capacity building and resilience for the community-based dementia care workforce. The main contribution to knowledge was the expansion of capacity building to include not only a focus on knowledge and skill, but also intrapersonal and organisational factors. A summary and integration of the results of the thesis will be described next to highlight how the thesis contributes to knowledge in the field.

Summary and Integration of Results

The current thesis applied a tri-theoretical approach to examine resilience and capacity building for community-based dementia care and found complementary results across three studies. A systematic review of dementia training interventions for worker and organisational outcomes (Study 1) found scientific rigor of evaluations was poor, a narrow focus of assessment, and suggested future interventions consider widening evaluation domains, including workers' psychological health and well-being. Sustainability factors that were

organisational in nature included workplace support (e.g., ongoing supervision or staff mentor). However, no clear pattern of effects was found for intervention outcomes. A phenomenological qualitative study of community-based dementia care workers proposed a core construct called occupational communion. This construct was defined as a sense of belonging based in social interaction at work that can assist adaptive coping. Workers reported strong social bonds with clients and a desire for social interaction with colleagues (Study 2 – Part A). A case-based study that employed a clinical psychology approach to the investigation described an overall resilient profile of dementia care workers, with a minority of workers displaying isolated distress (Study 2 – Part B). There was congruence between formal care workers and informal carers in their perspectives on present and future agenda of support services, and several suggestions for ways to improve dementia awareness, workforce development and organisational systems were made (Study 3). Collaboratively, the findings of the three studies show that wide spread improvements are required in community-based dementia care, for intervention research, workforce capacity and effective service delivery.

Workforce training

One way the thesis has contributed to knowledge for capacity building is by providing detailed suggestions to improve and expand dementia training. Overall, the findings about workforce training highlighted the importance of a broad but systematic approach to improve service delivery for people with dementia. There is a need for a wider range of training topics and improvements in evaluation and testing of training intervention effects. Further, increasing the number of qualified workers delivering care was highlighted as a concern, as low

numbers of qualified workers may undermine future workforce development approaches.

If workforce problems are expected to improve due to workforce development strategies, as international bodies suggest (WHO & ADI, 2012), then training interventions must be efficacious, in that they produce the desired outcomes consistently for all workers with lasting effects. Leading research groups are currently focusing their efforts on building a strong evidence base in this area with exemplary dementia training interventions (Beer et al., 2011; Beer et al., 2010; Chenoweth et al., 2011; Downs et al., 2006; Jeon et al., 2012; Kuske et al., 2009). The systematic review from the thesis highlighted only those findings from published papers that adopted randomised control trial designs to test dementia care interventions on work and organisational outcomes. This focus was adopted to reflect the current level of evidence for best practice of dementia training interventions and their sustainability. Despite this rigor, mixed results were found with no clear pattern across the identified RCTs and methodological problems were extensive which is a finding supported by previous research (Kuske et al., 2007). If the highest level of evidence in this setting does not offer clear direction for capacity building then much more evaluation is required of interventions that target both worker and organisational outcomes.

The findings from Study 1 have implications for the current training programs that form the basis of qualification and education within the sector, as it is unlikely that such training has undergone the rigor of scientific testing inherent in an RCT. For example, the Australian Dementia Care Essentials program, despite reaching a vast number of employees, was not randomised and results published lacked details of assessment and evaluation processes (Doyle et al.,

2009). Further, the preliminary results related to worker engagement rely largely on anecdotal evidence (Fleming & FitzGerald, 2009). More rigorous research in this area is required, particularly due to the dearth of interventions in the community-based setting (Elliott et al., 2012), which is a section of the Australian aged care sector expected to swell with demand due to ageing in place (Henderson & Caplan, 2008) and models of consumer directed care (Rees, 2008).

Dementia training in Australia is in need of a comprehensive overhaul. Current training programs aimed at residential and community care workers in aged care are generally task specific and focus on providing workers with knowledge on caring for older adults. Doyle et al. (2009) argue that this method avoids teaching workers how to generalise their skills to new situations or ways to broaden their perspectives to discover that there are multiple ways to approach the same situation or problem. In addition, previous efforts have been made to examine course content in the vocational education and training setting with poor response rates from industry training providers (Doyle et al., 2009; Finch et al., 2006). A commendable approach to the review of dementia knowledge and skills of the direct care workforce in the United States, Florida was adopted by Hyer et al. (2010) and may provide a model for credentialing dementia training for the Australian setting.

It has been established that there are a range of effective ways to care and support people with dementia over the course of their disease progression; from diagnosis to death (Andrews et al., 2009; Bartels et al., 2003; Conn et al., 2006; Mittelman et al., 2008). However, these strategies have not yet become an integral part of services delivery (Downs et al., 2009). This may relate to the lack of highly qualified professionals within the dementia care setting, who can offer direction

for implementation of evidence-based practice. The community setting may experience this lack of quality more so than acute and residential aged care. For example, the systematic review (Study 1) indicated a need for higher quality research in the community setting, and Colombo et al. (2011) reported qualifications are generally lower in the home and community sector compared to institutional settings. Thus, a lack in quality exists for levels of professional training and research approaches in the community care sector. Therefore, recommendations to improve capacity building and resilience for the dementia care workforce may be to enhance the quality of research into health service delivery, training and education, particularly in the dementia care setting. If practice is to improve in the delivery of care to people with dementia, the industry must begin to employ highly qualified professionals that can offer strong leadership regarding the translation of research into quality service delivery, particularly for the home and community care setting. For example, doctoral and masters trained psychologists and advanced nurse practitioners are well placed to perform such roles, considering the strong focus on a scientist practitioner model (Belar, 2000) throughout these postgraduate degrees.

While Study 1 reviewed interventions that were tested following the ideal study design (RCT; NHMRC, 2000), many education and training programs are not based on such rigor. Therefore, it is often difficult to determine intervention effectiveness due to a plethora of uncontrolled variables. However, even if such training programs were evidence-based there is no guarantee that they will reach the workforce considering the lack of regulation, accreditation and professional guiding bodies to enforce and provide incentive for participation. Helmes and Pachana (2006) describe the example of psychology training where multiple

drivers of both university-based training programs as well as clinical placement settings, including health care funding, registration/licensure boards, discipline-based peak bodies, advocacy groups and professional accrediting bodies have an impact on training. Thus, a comprehensive approach to training is required whereby organisational systems and governing bodies are established to support the translation of evidence-based research to improve quality within aged and dementia care services. These governing bodies may focus on the development of and adherence to evidence-based guidelines for training and workplace standards in dementia care that ultimately result in improved quality care and research translation. The overall approach to training in dementia should also include a wider focus than simply providing up-to-date courses and education, and follow previous models of continuing professional development (Fleet et al., 2008; Rampatige et al., 2009). If the dementia care workforce lacks a professional identity and associated governing and regulatory bodies, this approach (continuing professional development) may be a challenge. This is likely, considering there are existing problems inherent in continuing professional development relating to dementia for health professionals with well established identities (UK nurses and social workers; Pulsford, Hope, & Thompson, 2007). The Florida example (Hyer et al., 2010) where legislation mandates dementia training for all direct care staff based in a range of settings (i.e., nursing homes, hospice, home and health care) demonstrates the role governing bodies can play to enhance workforce knowledge and skills. Thus, training interventions that aim to improve worker skills and capability, and organisational preparedness must operate within wider industry quality control systems that without reform are likely to impede implementation success and sustainability.

Training for the dementia care workforce needs to be more specialised by including intervention topics that are comprehensive and cover a range of areas. Findings from the current series of studies suggested that training interventions should focus not only on dementia knowledge, they should also include topics related to interpersonal interactions with people with dementia and their informal carers. This may include training in how to manage intimacy associated with personal care, and emotional regulation associated with grief and loss. Covering topics that include ethical principals in care practice such as managing professional boundaries were identified as a need (Study 2 – Part A). These findings converge with previous research from Wellin (2008) that while many training programs provide practical skills on how to perform particular job tasks associated with basic nutrition, infection control, and manual handling techniques, they fail to include topics on resident rights, ethical concerns, dementia care, family stress issues, communication and spirituality. In addition, workers identified several types of training they were interested in attending in the future, of these was caring for CALD patients and families, also found to be the least attended training area by workers. Informal carers also expressed a desire for care workers to be more culturally sensitive. These results are supported by similar findings from the Dementia Care Essentials program and the Conversations on Ageing focus groups (Doyle et al., 2009; Yates, 2012). Delivering services to people of CALD backgrounds need to be improved by enhancing the skills of the workforce, particularly because this proportion of the Australian population is increasing (ACSA, 2011).

Results from Study 2 – Part A and 3 showed workers wanted to attend training in mental health issues concerning patients and family members, while

informal carers wanted specialised psychological support to manage the effects of the caring role on their personal well-being. These findings may relate to a perspective presented by King (2007) where regulations and service requirements have created a shift towards care delivery that is focused on the physical health needs more than the social and emotional care needs of patients and carers. In a review of nursing home training of staff (Kruske et al., 2007) only one of 21 studies focused on mental health issues (Rosen et al., 2002). In particular, the residential care environment rarely has a focus on staff training in the appropriate use of mental health screening measures, influencing detection and treatment of mental health disorders (such as Major Depressive Episode and Alzheimer's disease), and development in this area may be quite limited and not viewed as a high priority (Pachana et al., 2010). Similarly, a lack of mental health training was found to extend to the primary care setting where a need was identified to improve the knowledge of general practitioners with regard to screening and investigating late life depressive symptoms and managing dementia (Wijeratne & Harris, 2009). Further, Jones et al. (2007) acknowledged that there is a lack of training in mental health in aged care.

Study 2 – Part A found dementia care workers desired consistent and good quality supervision from senior workers. Thus, leadership training for case managers and senior staff may also form an essential part of workforce development. Quality supervision and support from the organisation was perceived by workers as an integral part of coping with high job demands. Previous research supports these findings showing that leadership within the work setting plays an important role in employee job satisfaction, well-being and sickness absences (Kouppala et al., 2008). A systematic approach to building

leadership qualities (Aberdeen & Angus, 2005) within the aged care dementia sector has been championed by Angus (2009). Employees expect their leaders to be reliable, honest, supportive, visible, passionate, collaborative, flexible and competent (Roberts, Nolet, & Gatecliffe, 2008). Therefore, training that focuses on building these traits in leaders within dementia care are likely to contribute to better work environments where workers are satisfied and lower levels of staff turnover exist. Considering the low levels of supervision support for workers in dementia care services (Hussein & Manthorpe, 2011), improving access to resources that promote mentorship and social interaction may be a valid approach for the future.

Training that has a comprehensive focus, and not only includes dementia knowledge, but also interaction with consumers and worker self-care was highlighted as a need by the findings of Study 1 and 2. There are similarities between these findings and the core dementia care competencies developed by Tsaroucha et al. (2011). In particular, competency numbers four and five, which included interaction with individuals with dementia and interaction with carers/families. Whereas, competency number six included a focus on dementia worker personal development and self-care. When considering a competency approach, it is necessary to expand training beyond knowledge to include practical skills that focus on social interaction. Further, eliminating the potential impact of recruitment and retention issues is likely to ensure sustainable practices. Therefore, the findings from Study 1 and 2 add to the area of training for capacity building, as they suggest it is necessary to provide adjunctive resources that relate to organisational variables such as social interaction and leadership.

Occupational communion

A key finding from Study 2 – Part A was the identification and description of a construct called occupational communion. The findings about occupational communion broadened the approach to capacity building by focusing on the importance of social connectedness in care work. Job satisfaction and high rewards from work tasks appeared to be based in social interaction and relationship building. While workers showed strong social ties with clients, the opportunity to build relationships with colleagues was weak. This finding supports previous findings about workers' commitment to their clientele and caring (Howes et al., 2008; Mittal et al., 2009) and how it is integral to worker commitment and satisfaction (Vernooij-Dassen et al., 2009).

Findings also suggested that workers lack a sense of connection with their colleagues possibly due to the independent and isolating nature of work. These factors are inextricably linked to the flexible nature of the job, which was also found to be a strong reason for job attraction such as work-life balance. However, the lack of social interaction with others completing the same core job tasks may in the long-term be detrimental to this workforce. A lack of professional identity, where workers can share and learn from each other about particular care strategies while feeling supported socially, may contribute to retention problems within the community-based dementia care workforce (Lindeman, 2009). Providing avenues for workers to achieve social connection at work, that extends from clientele to also include colleagues, may assist in coping and adjustment for workers to manage high job demands. Results from Study 2 - Part A showed that workers desired more contact with other professional carers to exchange caring ideas and establish a reflective practices approach. In particular, workers wanted to have

regular group meetings with other professional carers to discuss their clients' needs and approaches to care. These findings suggest that future services that aim to improve capacity and resilience for the dementia care workforce must encourage the establishment of professional bodies that encourage collegial support. Without such avenues, employees may be unable to use social comparison as a way to moderate their behaviours, which may lead to less favourable outcomes in care, or for the workers' self-interests. A recommendation for future dementia care services is to encourage the development of professional bodies for dementia care workers.

Extreme forms of communion were found in Study 2 – Part A when workers were focused on clients to the exclusion of self-interests such as training and job development. It appeared that unmitigated communion (Helgeson & Fritz, 1998) occurred when workers wanted to meet their clients' needs, which in some cases involved bending professional boundaries and organisational guidelines. Further, some workers did not want to attend training (self-interest) as it would mean re-scheduling their care roster so that colleagues cared for their clients. Some workers were worried about the care their clients would receive (others' focused) from their colleagues, considering they did not have an established caring relationship. While organisations want their workers to attend training (organisational goal or value), carer workers may not have the same desires, particularly if this interferes with their commitment to their clients (worker goal or value). Therefore, the congruence between workers' and organisations' goals and values about caring may act as a mediator between extreme and healthy forms of occupational communion. Thus, the concept of occupational communion sits at the inter-face between social and organisational psychology and may have

implications for resilience and sustainability of the dementia care workforce. In further support of this relationship, previous research (Hatton et al., 1999) implied an association between P-O fit and communion at work, as social relationships were perceived by disability service workers as integral to the ideal organisational culture. Both disability and dementia care workers desired social relationships at work. The convergence of results between the current investigation (Study 2 – Part A) and those of Hatton et al. (1999) suggest social connectedness in the work context appears to be important for organisational cultures within the supportive care sector.

Client focused social ties appear to enable care workers to perform challenging care tasks that form part of high job demands. For example “social chit chat” and a “relationships built on trust” to help clients feel comfortable to receive care and less likely to refuse care. Therefore, occupational communion may be important for job performance, especially when performing care tasks that are based in social interaction. Hansebo and Kihlgren (2002) found similar results for nurses based in the residential care setting, where meaningful communication that was focused on communion, not only involved a strong relationship between nurse and patient, but led to positive care outcomes such as nurses’ turning care refusals into consent to care. Encouraging workers to have professional social connections with their clients may be essential for quality care delivery by the dementia care workforce.

Seeking communion may serve as a protective factor at work as there is tentative evidence that workers may strive for communion as a coping strategy to deal with job stress. Halbesleben and Bowler (2007) found that when workers in high stress jobs experienced emotional exhaustion, they sought to increase their

resources in communion (such as social interaction with colleagues). While findings by Halbesleben and Bowler (2007) were based on fire-fighters, they appear to support the results of Study 2 – Part A and Part B that indicated community dementia care workers desired social support from colleagues to cope with high job demands including working in isolation. Further, having little opportunity for interaction with colleagues provided few chances to de-mystify perceptions about co-worker skills and influenced workers' likelihood of attending training. Therefore, implications suggest that communion in the work context where there are high demands may serve to buffer against poor employee well-being and play a mediating role in job performance and development.

Dementia specific job demands and resources

Results from Study 2 – Part A provided a full description of the unique job demands and job resources for community-based dementia care workers informed by organisational psychology theory (JD-R model; Demerouti et al., 2001). Job demands were described as the challenges faced by dementia care workers in their job roles. Workers' were consistently expected to rise to challenges such as being alert to changes in care recipients and the environment, dealing with strong emotions such as grief and loss, and isolation, as well as navigating the boundaries of the professional care relationship to meet the needs of their clientele. Similar job demands were found previously by Demerouti et al. (2001) who argued that they require sustained physical or mental effort by employees, and have the potential to result in certain physiological and psychological costs (such as burnout).

Overall, job resources included several ways workers perceived their roles to be supported by both personal (e.g., job attraction, past caring role and strong

commitment to the organisation) and organisational factors (e.g., sound perceived organisational support). Generally speaking, while workers perceived good access to resources to support them in their care roles, they also acknowledged specific areas needed improvement such as job conditions (e.g., salary and feeling undervalued) and resources (e.g., supervision) which they considered worthy of organisational investment. Similar job resources were found by previous research, where job resources served as health protecting factors that contribute to and maintained worker well-being (Demerouti et al., 2001). Even after encountering high degrees of workload, job resources have been found to enhance achievement of goals at work, reduce the costs associated with job demands, and stimulate personal growth and development (Demerouti et al., 2001). While job demands highlighted by Study 2 – Part A identified the multiple challenges of the paid care role, job resources appeared mostly to mediate the possible effects of these demands on the workers' psychological function. Thus, the JD-R model applies not only to the human resources and general health settings (De Jonge, Le Blanc, Peeters, & Noordam, 2008; Demerouti et al., 2001). The JD-R also has strong relevance for the dementia care setting where qualifications, salaries and access to consistent supervision are low for dementia care workers in comparison to general health workers. Further, improving the quality of and access to job resources is likely to reduce turnover associated with disengagement and exhaustion in the dementia care workforce, while maintaining a resilient and committed workforce. Thus, organisational support must be considered an important aspect of capacity building and resilience and it may be recommended that improvements in organisational support for the workforce are a necessary part of aged care reform.

Workforce resilience

The current series of studies found dementia care workers face high job demands. Dementia care workers may experience trauma vicariously, as their roles inevitably expose them to a decline in health of their care recipients and the adjustment issues of their informal carers and family members. Dealing with loss and grief associated with dementia was considered one of the challenges of the job. Despite experiencing high job demands and potentially being exposed to trauma, most dementia care workers showed a resilient profile (Study 2 – Part B). While many workers in aged care may quit their jobs if they feel unable to provide quality care and feel dissatisfied in their roles (Vernooij-Dassen et al., 2009), those who feel committed to clients (Howes et al., 2008) and socially connected, adjust to the challenges of their roles and remain working in the sector. Several resilience factors may relate to this difference between workers who stay and those who resign. Study 3 showed that resilient workers shared several characteristics and intrapersonal factors included high occupational self-efficacy, rewarding job tasks, positive affect (e.g., feeling enthusiastic or interested) at work, being in a committed relationship, having a dual income, and higher levels of education and knowledge of dementia. Resilient workers also showed strong commitment to work. Organisational factors that influenced resilience included a good fit with employer agenda and a sense of support through promotional opportunities.

The thesis extended the view of capacity building to include workforce resilience. Findings from the current series of studies suggested that relationships are an important part of the resilient profile for the dementia care workforce. Particularly as workers with positive adjustment were more likely to be married or in a committed relationship than not. In addition, workers highlighted a coping

need for collegial social interaction. Study 2 – Part A also found workers considered they “get more from their clients than they can give” and how “the interaction with people is the best part of the job”. Consistent with these findings, Hartling (2008) proposed that “resilience can be strengthened through engagement in relationships that enhance one’s intellectual development, sense of worth, sense of competence, sense of empowerment, and, most importantly, sense of connection” (p. 51). Thus, a resilient workforce is one that has supportive professional relationships that foster personal growth and assist employees to cope with workplace adversity. Further, Weaks et al. (2005) proposed that practice-based supportive frameworks to enhance relationships were essential to creating more positive models of care.

Stage of caring career can influence the resilience of workers to adjust to high job demands. Study 2 – Part B found later career workers (employed five years or more) were more likely to show positive adjustment than early career workers, which was supported by similar findings by Zimmerman et al. (2005). Previous research has established that job stress mediates performance (Gilboa et al., 2008). In the dementia care setting it may be that employees lack of knowledge of what is expected of them in their daily job tasks constricts their ability to meet job expectations and in turn leads to negative emotions. This has previously been described as role ambiguity and refers to the extent to which employees are uncertain about their job functions and responsibilities (Chang & Hancock, 2003). In the community-based dementia care setting, role ambiguity may relate to confusion over expectations in different clients’ homes. Role ambiguity may be particularly applicable for early career dementia care workers. In contrast, high occupational self-efficacy formed part of the resilience profile in

the current series of studies. This is supported by previous research that shows individuals with high confidence to cope with chronic stressors have better adjustment than those with low confidence (Turner et al., 2007). The same processes may be at play with regard to workers' occupational self-efficacy. Therefore, assisting workers to manage role ambiguity by ensuring they have sufficient knowledge and confidence in new tasks is likely to contribute to resilience at work, particularly for early career workers. Education and training formed part of the resilient workforce profile, particularly knowledge in dementia. Having access to information that can help workers perform their care tasks by understanding the experiences of their clients with dementia may lead to high levels of occupational self-efficacy. Thus, there are training implications associated with education that assist job development and enhancement, and also improve preparedness and resilience for the workforce.

A good fit with employer agenda was found for a resilient workforce (Study 2 – Part A and Study 2 – Part B). Community-based dementia care workers' have little interaction with the physical workplace as their roles are completed in the personal domain of care recipient's homes. This characteristic of the workforce does not appear to influence employees' sense of fit with organisations goals and values. In fact, resilience was associated with high congruence between workers' and organisations' goals and similar findings have been reported for effective organisations (O'Driscoll et al., 2003b). When workers' perspectives on care delivery match those of the organisational mission, workers were satisfied and found their jobs rewarding. It maybe that enhancing congruence aides organisations to function effectively, as well as enables preparedness for

organisational change. Those workers likely to thrive in the face of high demands may be those engaged with organisations' values and future directions.

Perceived organisational support was also found to be relevant for resilience, in particular workers with positive adjustment also showed high promotional opportunities (Study 2 – Part A and 2 – Part B). A meta-analysis indicated that four major categories of beneficial treatment received by employees were associated with POS. These related to perceptions of fairness in the way organisations managed workers, access to support from supervisors, and organisational rewards such as recognition and favourable job conditions. In turn, these factors (POS) were related to outcomes that were favourable for employees and included job satisfaction and positive mood, as well as the organisation, such as, affective commitment, performance and lessened withdrawal behaviour (Rhoades & Eisenberger, 2002). Thus, a resilient workforce (high job confidence, rewards and promotional opportunities) may be related to organisational commitment, as few workers with resilient profiles intended to resign from their jobs (Study 2 – Part A and 2 – Part B). In addition, results from the current series of studies suggested leadership, a type of organisational support may be more important for workers with isolated distress than global resilience profiles. Guidance and mentorship may be a greater need for workers with isolated distress to help alleviate burdens associated with decision making and problem solving as part of the paid care role. Therefore, organisational support appears to be integral to the resilience of the community-based dementia care workforce.

Whether workers are committed, engaged and willing to attend further training may also be related to perceived organisational support which is important considering further education and training formed part of the resilient profile. If

organisations are able to offer support to workers to participate in training, attendance at conferences and other professional development opportunities, this may in turn lead to workers' positive perceptions of their organisation. Most workers were satisfied with training experiences and this contributed positively to how they viewed the workplace, particularly when employers paid for workers to attend workshops (Study 2 – Part A and 2 – Part B). Workers who feel supported by the organisation are often willing to put more effort into their job tasks (Eisenberger et al., 2001). This may include participation in training and taking on additional roles, and care workers may also feel a sense of duty to remain working with the organisation in the future.

Aligned care expectations: Informal carers and formal care workers

Overall, informal carers' and formal dementia carer workers' perspectives align to show carers want improvements in access to information and support, workforce training and service delivery in the community setting. In addition, both carer types engaged in similar practical caring tasks despite being a family relative or in a paid role, which was supported by findings from a community-based study on nurses caring for the general elderly by Ward-Griffin (2002). One exception to the pattern of strong alignment was found regarding the care relationship, where workers appeared to be motivated by a social need to interact with people, whereas informal carers did not mention a similar feature. However, this was not supported by previous studies as qualitative research (Benbow et al., 2011) found that relationships with staff were important for informal dementia carers and their care recipients. Benbow et al. (2011) reported that people with dementia and their carers wanted a friendship with carer workers, so they could trust and rely on them for support. Despite these preliminary findings, further research into the care

relationship is required to advance understanding about the influence of care interactions on quality care in the support role. This research on the caring role may provide insights for workers and informal carers to enhance their roles to deal more effectively with the challenges they experience.

Study 3 found informal carers of people with dementia were generally satisfied with current support services, but they wanted improvements in many areas of service delivery, both presently and in the future. In particular, formal care workers and informal carers perceived factors such as workforce development and organisational changes as necessary to prepare for future needs. The findings from Study 3 suggest that informal and formal carers desire improvements in the consistency of care for people with dementia. This was highlighted as a high priority due to the nature of the disease. For people with dementia, familiarity and regular routines play an integral role to maintain quality of life and reduce psychological distress. One way consistency of care may be improved is through better collaboration across services by adopting a multi-disciplinary focus. Thus, a recommendation that aims to improve service delivery for people with dementia may be to encourage dementia care organisations to adopt a multi-disciplinary focus.

While carers aligned on most preparedness factors aiming to deal with the dementia epidemic, collaboration between the educational and health care sectors needs to improve. For example, in other health professional areas in Australia such as psychology, the regulation agencies, such as the Australian Psychology Accreditation Council (APAC) and the Australian Health Practitioner Regulation Agency (AHPRA) have assisted to provide this connection between the education and health arenas. A lack of a similar system in aged and dementia care, in

combination with the diversity of services is likely to contribute to “total confusion” (Benbow, 2010, p. 307) of development strategies for the dementia care workforce.

Study 3 contributed to knowledge in the area of dementia care, as investigating informal dementia carers’ perspectives on present and future community-based service delivery, is a relatively new approach. Including consumers in service development and evaluation (Litherland, 2008) is considered a key development in health care service delivery. An international report discussed the importance of involving patients and carers in health reform. In discussing the transformative “scale up” of health professional education, the WHO and the US President’s Emergency Plan for AIDS Relief (WHO & PEPFAR; 2011) suggested that:

If a new effort to scale up health professional education is to really transform the health of nations, it must be a process of reform that is driven by the people and communities who are the users of health services, implemented by national authorities working with public and private educational institutions, and supported by a broad coalition of stakeholders (p. 10).

Thus, training reform does not only rely on the implementation of professional and governing bodies, but also on input from people requiring health services. Further, population health agencies need to be informing health departments and educational systems, who in turn should be providing incentives for training and education within areas of specified need. The WHO & PEPFAR (2011) suggest that this process should also be informed by the “consumer voice” representing current use of such health services. As an internationally recognised

health priority, dementia care is a disease with great impact upon population health.

Similar information and access issues were raised by informal and formal dementia carers to other international studies (Georges et al., 2008; USAA, 2011). Informal carers reported wanting more flexibility in service delivery so care plans could be tailored to their needs, while formal care workers wanted access to better resources for their clients and to spend more time with them. Barriers to accessing services for informal carers related to an array of reasons that generally showed that some carers felt disconnected from service providers. Informal and formal carers agreed that more information about the services available and better community understanding about dementia was needed. Improved community understanding about dementia (in particular carers' needs and available services) would help informal carers be more knowledgeable about available support through existing social and community networks. In addition, the findings from Study 2 and 3 not only highlighted a need for informational resources, results showed that formal and informal carers wanted more funding to allow a greater number of paid care hours for people with dementia. Overall, there was agreement that funding was needed to improve care delivery. Future services may require more funding to improve quality care, and this funding may extend to the research arena where quality care delivery and implementation of capacity building strategies can be tested. A recommendation for organisations that want to improve service delivery for people with dementia may be to increase their funding arrangements and further lobby for research into health services in dementia care.

Stigma of dementia has been found to increase the burden of the disease on carers (Werner et al., 2012). Therefore, accessing services may be more of a

challenge for dementia carers in comparison to other types of carers due to the stigma and lack of public awareness about the disease. Further, stigma has been found to extend to the professional setting where physicians often delay diagnosis of people with dementia (Kaduszkiewicz et al., 2009; WHO & ADI, 2012). Further, people fear receiving a diagnosis of dementia and can avoid seeking medical and professional help, as they worry a diagnosis may place them at risk of discrimination in the health sector (Phillipson, Magee, Jones, & Skladzien, 2012). Lack of public awareness not only contributes to carer disconnection with services but was also found to be in the top of ten factors viewed as a challenge to meeting Americas' National Alzheimer's Plan (USAA, 2011). Dementia often remains in the shadows and warning signs, misplaced anxieties and misconceptions must be overcome so that the hardship of the disease is not exacerbated by stigma and lack of knowledge (USAA, 2011). International bodies may consider the success of public health campaigns throughout history such as those conducted with HIV and cancer (Cameron, 2012), and consider a similar approach to overcome the negative effects of stigma associated with dementia.

Capacity building strategies

Findings from the current investigation offer a consensus of potential capacity building strategies for the dementia care workforce that aim to strengthen and develop workers. In particular, collaborative findings showed several strategies were relevant for the development of i) workers' skills and capabilities, ii) organisational support within care services and strengthening ii) recruitment and retention.

Dementia care workers' skills and capabilities may be improved by interventions that focus on several domains. Further education and training to raise

education levels and qualifications through tertiary and post-graduate courses will enhance worker capabilities. This may include advancing education of current and potential future employees. Education that is focused on improving dementia knowledge (including younger-onset dementia, the range of dementia diseases and effects on patients and carers across the disease trajectory) in particular, strategies to manage patient behavioural problems may also enhance worker skills. This may also include building employee understanding in communication and conflict resolution skills, relationships and interpersonal interactions, as well as ways to manage professional boundaries which may extend to ethical issues. Education for workers may also be focused on mental health of patients and carers and about working with people with culturally diverse backgrounds. Enhancing employee self-efficacy and self-care strategies are also relevant in order to develop skills that help worker to maintain positive psychological well-being. This may extend to include education in topics on emotional regulation and stress management, as well as how to activate social supports that are both personal and work related. Developing skills in these areas will assist workers to cope with emotional labour, role ambiguity and grief and loss and may prevent symptoms of distress and promote resilience. While most of these strategies relate to employees delivering personal care and support to people with dementia, other domains may be relevant for managerial level staff with the responsibility to provide the majority of supervision to employees. These include the development of leadership, mentoring and supervision skills.

Dementia care organisations need to provide several supportive functions that aim to build capacity. Providing opportunities for collegial social interaction through the provision of regular meetings to help cope with job demands such as

isolation, may potentially improve a collaborative care approach and assist towards developing a sense of professional identity. Financial and practical support to access further education and training appears to be important to develop a sense of perceived organisational support for employees, thus contributing to improvements in capacity. Providing clear career pathways for employees to be familiar with ways to develop their job roles are important for the development of the workforce. In particular, pathways that stem both from the employer and the education and training sector, such as vocational education and training, and university-based settings. Induction programs to orientate and support early career workers may help to promote P-O fit and improve retention. Organisations may consider developing programs that promote consistent leadership, supervision and mentorship so that employees have access to quality advice and guidance. Further, programs that sponsor incentives or recognition of workers efforts (e.g., to acknowledge uptake of additional evening and weekend shifts) may enhance employee perceived organisational support and in turn commitment to work, and engagement in new roles.

Some organisational support resources for capacity building may be more reliant upon funding structures and subsequent policy. The current investigation identified several of these types of resources such as the improvement of employment contracts and salaries to provide workers with greater job security. Ensuring equitable provision of resources such as access to transport is also likely to enhance employees' job conditions. Providing practical resources for clients to comply with ageing in place (e.g., electronic lift chairs) may also be important for worker satisfaction and intention to stay, considering care workers motivations to leave work are based in appraisals of their ability to deliver quality care. Allowing

workers more allocated time with clients may also contribute to workers' perceptions that they provide adequate support to the people they care for. A less narrow focus on the practical care need of patients and instead an employee agenda that includes the social and emotional welfare of clients to include service delivery requirements and job tasks that promote this, may be important for capacity building. In addition, system improvements including better care co-ordination, flexibility in care delivery, and increases in funding for care packages will provide adequate resources for workers to manage their job demands. Further, the establishment of professional bodies that represent the worker and the consumer independently, and regulate qualifications and training were found to be important for capacity building and resilience for the care workforce.

Areas of overlap between worker and organisational domains were found to be particularly relevant for capacity building strategies that target attraction and retention of the workforce. In particular, improving the image of dementia care by improving pay and conditions, while maintaining positive perceptions of work-life balance (such as the flexible nature of work) to attract potential employees. This area also includes good P-O fit to ensure congruence of worker and employer values to assist commitment to work (e.g., induction and orientation programs) and job performance. Another approach to consider may be to promote occupational communion to develop a sense of professional identify among workers that may act as a buffer against the psychological costs of high job demands. Further, a focus on matching the social need of potential employees to the supply of the job as well as personal abilities to job roles may also be important for recruitment factors related to capacity building.

Strengths of the Research

While there are several limitations of the research, mentioned both in Chapter Three and within each study, there are also several strengths. The focus of the investigation on resilience and capacity building for the dementia care workforce is distinctive, as it implies a positive perspective. Further, the focus on the community-based dementia care workforce attempts to provide a balance to the literature that mainly focuses on workers based in primary and acute care, as well as a majority in residential care. While there is strong research informing best practice in dementia care, there is less for research that aims to inform training and development of the workforce expected to adopt such best practice principals. Thus, the current investigation contributes additional knowledge to the latter comparatively under researched area. Therefore, the current investigation meets a research area of specified need.

Following a tri-theoretical approach resulted in the identification of several core constructs found to influenced workers' job attraction, functioning and commitment to work (e.g., occupational communion, job demands and resources). Therefore, the organisational theoretical frameworks readily applied in human resource, clerical and health and human services settings appear to be relevant for the dementia care setting. Further, the application of clinical and social psychological constructs to the occupational setting in combination with organisational theories offered a unique view point and strengthened the current investigation. For a sector where collaboration and multi-disciplinary co-ordination are at best in preliminary stages (Fortinsky, 2001), the current investigation adopted a multi-discipline approach to provide a collective strength to determine the best ways to prepare the dementia care workforce for future demands. Following this

approach may bring forth advancements in the field, paralleling the way psycho-oncology research has developed over the past ten years and anticipated to continue to develop further in the translational arena (Cao et al., 2011).

There is a gap in research in the area of dementia training and education that aims to improve both worker and organisational outcomes. The current investigation is the first to adopt this approach following a systematic review of dementia training interventions (Study 1; Elliott et al., 2012) and is likely to be a key focus for sustainable practice. The methodological analysis of studies included in the review was detailed and followed a systematic approach that aimed to guide an agenda to overcome methodological obstacles in dementia care training. Study 1 was very focused and may have an in-built bias towards positive and significant results, which is commonly found in systematic reviews. Despite this, the findings contribute to the field by extending the view of capacity building to include a combination of worker personal variables (such as knowledge and well-being) and organisational climate (such as organisational support and retention).

The rigor of the qualitative studies (Study 2 – Part A and 3) was high, considering the strength of the coding approach as evidenced by inter-rater reliability measures, and adherence to criteria from the Critical Appraisal Skills Program (CASP; 2002). Most previous studies exploring communion in the work context did not have a dementia focus and were not set in the community, and had adopted the use of surveys, therefore, Study 2 – Part A applied a qualitative focus to describe in-depth the issues most pertinent for community-based dementia care workers. Study 2 – Part A was the first to apply the theory of P-O fit to the

community-based dementia care workforce for review of capacity building factors.

While some studies have reported the psychological distress of dementia care workers (mainly those based in residential care; Pitfield et al., 2011), Study 2 – Part B applied a case-based clinical psychology focus to determine resilience and distress for workers' psychological well-being. Despite the small sample size employed in this study and the problems this has for quantitative research, the findings from Study 2 –Part B informed the area of workforce resilience in dementia care. The case-based clinical psychology approach is distinctive from most literature in the field as it employed the use of psychometrically sound measures to enable a comparison of dementia care worker function to clinical and normative samples. While reviewing the literature for concepts that may be relevant for strategies that may contribute to resilience at work is not unique (Jackson et al., 2007), the extension of the current research to inform capacity building intervention design is considered a strength.

Implications for Future Research, Translation and Policy

Research on capacity building and resilience for the dementia care workforce that is based in scientific theory will provide some guidance for care services. The scientific evaluation of interventions that aim to improve existing service delivery will also guide improvements in dementia care for health services. Research alone will not solve the issues faced by the dementia care workforce. Thus, translation of research into practice is an essential component in this process. Translation is often viewed as the bridge between research and policy (Mirvis, 2009). Further, policy has the power to provide a system that facilitates the adoption of a desired approach with proven outcomes, where the

implementation of evidence-based practice is regulated and long lasting.

Collaboration across these levels is known to contribute to effective change in the health setting. Therefore, a consideration of the implications of the current investigation on future research, translation and policy follows.

Future research

If the sector is to move forward on the most prevalent and current issues facing the dementia care workforce, namely problems with recruitment and retention and capacity building, several approaches to future research are necessary. Future research should address the disparity in representation of the community sphere, especially considering the trend of ageing in place and subsequent community demand. A range of other issues should be addressed for intervention research including methodological weakness, atheoretical approach, a narrow view of worker outcome domains and a lack of consideration for the bi-directional relationship between workforce variables and organisational culture.

Intervention effectiveness, with RCT designs recognised as the gold standard (NHMRC, 2000), will be essential to establish evidence-based training approaches. Following recognised reporting methods such as the CONSORT for RCTs (Altman, Schulz, & Moher, 2001) may guide research in this area. Clustered RCTs may be useful to overcome some barriers associated with randomisation in workforce studies such as masking, as well as fidelity concerns. The review highlighted the importance of pursuing a mixed methods research approach to understand more about intervention mechanisms and or mediators of intervention response to refine future development. In particular, future studies that solve problems with defining and testing intervention components and identifying the best areas to target for enhancing adjustment. Hence, the current research adopted

this approach (Study 2 – Part A and 2 – Part B). Future research may include replication studies and attempt to adapt and test the findings about the aforementioned capacity building strategies from the current investigation to form a multi-component intervention using an RCT design.

A key finding from the current investigation, occupational communion may be particularly relevant for women's caring careers and future research is needed to explore the relevance of this concept for men in formal care. To determine reliable change associated with interventions that target occupational communion, further investigation is required on measurement approaches of this concept. Developing assessment tools or adapting existing tools that measure agency and communion to the work setting should be included in future research, with particular focus on review of psychometric properties to gauge reliability and validity of the construct. Whether or not intervention components informed by occupational communion are effective to improve skills and capabilities for all workers or a subset of workers is also relevant for future intervention research.

The effects of stress associated with the dementia care role on retention and turnover should further be explored in the dementia care workforce, particularly with reference to psychometrically sound measures. Future research through replication studies (following a case-based clinical psychological approach) are needed to closely examine a larger number of the workforce that experience distress in the community-based dementia care setting. This focus may help to establish further understanding about reasons of employee resignation and burnout. Further research into the care relationship is required to advance understanding in the variables that may contribute to situations of conflict that make for additional strain on the caring role. Identifying processes of interaction

between formal care workers and informal carers and their care recipients that improve quality care delivery may also be relevant for future research.

It may be possible to develop a model of capacity building for the dementia care workforce, by conducting quantitative research into several factors identified by the current investigation, such as JD-R, organisational support, occupational communion and resilience. Quantifying the relationship between these factors and the amount they contribute to retention may create the missing foundations for capacity building intervention research. Further, adopting better national data collection processes for Alzheimer's disease and other dementias similar to those for cancer registries (e.g., Australasian Association of Cancer Registries; AACR, established 1982) will allow for greater sophistication in research and evaluation in dementia care. Prevalence data about patients and carers may assist to specify level of need, and in turn lead to targeted research that is of higher quality. Improved data collection on the dementia care workforce, one that is diverse and ranges across several care systems is also needed for enhancement of future research, both in Australia and internationally (AIHW, 2009; Montgomery et al., 2005). The overall priority of research investigating development strategies for the dementia care workforce is to conduct high quality research that will contribute to a strong knowledge base to inform evidence-based training and practice. An issue closely related to evidence-based practice is translation of knowledge into work practices.

Translation

The first step of translating research into practice is to have adequate knowledge, based in scientific evidence that is appropriate for adaption to the practice environment. Thus, capacity building and resilience for the dementia care

workforce must firstly advance to avoid “premature action”. This is a challenge for translation and has already occurred in the dementia setting regarding new drug developments, mild cognitive impairment (MCI), and dementia risk factors which has led the general public to be sceptical of scientific outcomes (Draper et al., 2009). The second stage of the translation process involves interaction between multi-dimensional stakeholders including, researchers, educators, clinicians, care workers, consumers and policy makers, where information exchange is central.

While evidence from research exists for best practices in dementia care delivery, these are not often followed. This may be due to the challenges that exist for translation of research to practice. Draper et al. (2009) found that challenges relevant for dementia knowledge translation included difficulties in determining responsibility for translation (researcher versus clinician or educator), a lack of resources (such as allocation of costs per stakeholders operating in low funding environments), and a low qualified dementia care workforce, in combination with the paucity of research about effective translation strategies. Despite this, there is some evidence that suggests several factors can improve worker acceptance of new interventions or service delivery strategies. These factors are diverse and have been found to include the social prestige of the intervention, as well as the compatibility or similarity between the values promoted by the intervention and the values experienced by workers. The observability of results to others, as well as the adaptability of the intervention to the environment were also considered important factors related to acceptance of new interventions by workplaces (Greenhalgh et al., 2004). Therefore, if workforce development strategies are to be translatable to practice a plethora of variables based on acceptance of the

intervention by workers, consumers and service providers, as well as organisational culture should be considered.

Training interventions that target change in dementia care workers will need to be informed by workers' perspectives of their needs. If the final aim of improving dementia care workers' capabilities is to improve the quality of care delivered to consumers, then it is also necessary that training interventions be informed by the patient and carer views. This approach was adopted by the current investigation and supported by other research (Benbow et al., 2011), and should be followed by the research community to improve the adaptability of the research for translation to practice. Previous research suggests that for interventions to be accepted by the target audience, a clear link between the creators of an intervention and those receiving it is needed (Greenhalgh et al., 2004; Lomas, 2011). Involvement of patients and carers in the design and implementation process of public services is also known as coproduction, where there is potential to improve the quality and responsiveness of public services (Ottmann et al., 2011). Therefore, when devising ways to build capacity in dementia care it will be necessary to consider these principles.

Adopting an approach that acknowledges both worker variables and the organisational climate may contribute to translation of capacity building and resilience research for the dementia care workforce. Further, a consideration of organisational psychology principles is likely to be beneficial during the design of interventions, such as perceived organisational support. Draper et al. (2009) explained that the status quo of the organisation is maintained despite the fact that an employee has gained knowledge and wants to change practice, particularly when the workers' efforts to change are not supported by their colleagues and

employer. Thus, for translation of research to practice to be successful, it is important to also focus on the organisational climate with a preference for workplaces that promote an evidence-based approach. Similarly, this will mean that senior workers and leaders within the organisation are also made susceptible to intervention implementation. An extension of the current research may be to consider the managerial and organisational leaders' views and further evaluate service delivery to determine a multi-level perspective to ensure translation potential. Future research into service delivery and organisational changes associated with preparedness for the ageing population must be viewed from all levels (e.g., formal care worker, informal carer, care recipient and senior workers/supervisors and the service provider perspective), if only to enable a coproduced message that is likely to contribute to implementation success.

The success of research translation to the practice setting may be based on relationships between social scientists and practitioners. Thus, employees who embody this approach (scientist-practitioner) are likely to be important for implementation success. Dobbins et al. (2009) discuss a *knowledge broker* defined as a role that:

Provides a link between research producers and end users by developing a mutual understanding of goals and cultures, collaborates with end users to identify issues and problems for which solutions are required, and facilitates the identification, access, assessment, interpretation, and translation of research evidence into local policy and practice (p. 1).

Employing dedicated knowledge brokers in the dementia care sector is likely to be challenged by recruitment and retention issues as well as poor resources, and evidence of their effectiveness is currently based on qualitative studies (Dobbins

et al., 2009). However, there may be implications for the types of skills dementia care workers, or their supervisors should develop that focus on interpreting research to the practice setting. A qualitative evaluation of the effectiveness of a dedicated role for translation (e.g., knowledge broker) found several common themes. These included relationship development, ongoing support, customised approaches, and opportunities for individual and organisational capacity development (Dobbins et al., 2009). These themes describe a fostering role and may have related to the initial introduction of the role to the work environment. Further, it is unknown if these same factors are essential over the long-term.

Interpersonal interaction and quality work relationships where workers advocate for the cause (i.e., evidence-based approach) appear to be important for translation of research into practice. Findings from a literature review by Thompson, Estabrooks, and Degner (2006) support this and suggested that people who are opinion leaders or champions who advocate with overwhelming enthusiasm and have strong connections, while providing solutions to problems, play key roles as agents of change. Following a multi-discipline approach may also influence implementation success as there is a greater chance that key stakeholders, integral to dissemination, find familiarity (or compatibility - similar values and beliefs; Greenhalgh et al., 2004) with the intervention. For example, collaboration between nursing, psychology and business may ensure interest from care workers, clinicians and service providers.

Whether or not outcomes from intervention research can be replicated through service implementation is of high priority. Placing this as a priority may lead to improvements in the organisational capacity of services to cope with the predicted high demands in the aged and dementia care industry. During

intervention implementation, services undergo several levels of change, which Lomas (2011) suggested can be facilitated when networks and partnerships are primed to deliver and receive tailored messages. Two key factors will be fundamental for translation of dementia training interventions. Firstly, establishing evidence-based knowledge in dementia care training, and secondly, ensuring collaboration across a multi-dimensional setting for dissemination.

Policy

Pervasive and long-lasting practice changes require a broader approach than interventions targeting dementia care workforce improvement at both a worker and organisational level, these require changes in public policy (Gilliard, 2008). In Australia and the United Kingdom, the origins of dementia care policy have struggled for clear identification for the last 30 years and have been divided between varying services and areas of responsibility, such as divisions between mental health and aged care services (Gilliard, 2008; Howe, 1997). Recent policy developments in dementia care have included political promise of reform with funding and action plans through public statements and documents detailing a committed focus on dementia in health care (DH, 2009; Horner & Doyle, 2011). While several countries have detailed action plans for dementia, internationally these are the minority. Of those countries that do have dementia action plans, only seven have a detailed focus on the development of the workforce (WHO & ADI, 2012). The findings of the current investigation inform policy that is relevant for the dementia care workforce and service delivery that is community-based.

Brodaty and Cumming (2010) reviewed government policies and papers about dementia care services in Australia and advised that the area is well developed but gaps remain. The findings of the current investigation showed

formal care workers and informal carers agreed that improvements in service delivery were needed across the sector. Dementia awareness in the community and the general health and aged care sector were highlighted by the current investigation as essential for future preparedness, as were improvements for workforce development and organisational care systems. Brodaty and Cumming (2010) supported these findings and suggested that future developments in policy should aim to increase awareness, reduce stigma, enhance carer support, improve timely diagnosis and support for special population groups (e.g., Indigenous and non-English speaking communities, younger onset dementia). Flexibility in service delivery was promoted as an unmet need by carers in the current investigation, and was corroborated by previous research identifying inflexibility in the current model of community-based services (AUAA, 2011). Training desires of workers, matched carers need for workers with more skills in cultural diversity and mental health, and both carer types acknowledged more time to care was important for the future. Yates (2012) supported these findings and suggested that older Australians want a skilled and respectful workforce that has the ability to spend an appropriate amount of time to deliver care services that meet patients' and carer' needs. Thus, policies are needed that encourage training of the workforce in general and in areas of special need, as well as those that allow more flexibility in the current service model.

A key finding from the current investigation suggests that public health policy relating to the dementia care workforce should include frameworks that assist organisations to support their workforces. Health services policies and practices that recognise and aim to enhance occupational communion are needed and may overcome problems with recruitment and retention. For example, if

employees perceive strong organisational support this has a positive influence on job performance and commitment to work (Eisenberger et al., 2001; Rhoades & Eisenberger, 2002). Recruitment and retention problems may be symptomatic of a work culture that is insecure, undervalued and isolated. Thus, providing opportunities for workers to build professional relationships with colleagues (e.g., occupational communion) that act as a buffer against negative effects of challenging job demands and unsupportive work cultures, are likely to provide the strong foundations necessary for a committed and resilient workforce.

Policy developments must also consider ways to show dementia care workers they are valued for their roles and caring skills by providing commensurate remuneration. Overwhelmingly, international and national studies show dementia care workforces are disadvantaged, with a majority of female employees, low education and pay levels, as well as insecure job contracts (Martin & King, 2008; Montgomery et al., 2005). These findings were also shared by the current investigation in which it was demonstrated that workers felt undervalued. Kemper et al. (2008) suggested that in order to increase retention of frontline workers, policy makers should design public policies and management practices to increase pay and to improve work relationships for professional carers.

There is some promise regarding wage increases for care workers, particularly in Australia where recently, an equal remuneration order was approved by the Australian Fair Work Commission. This was considered an historic occasion where a pay rise was approved for social care workers in the community sector as they were found to be underpaid compared to public service workers engaged in similar jobs and gender was one of the reasons workers were undervalued (Noone, 2012; Schneiders, 2011). While this increase in pay does not

directly translate to the dementia care workforce, some workers may fall within this sector. Noone (2012) reported the original submission “specifically included tasks performed by women in the aged and community care sector in its list of duties that were labelled as having a ‘female characterisation’ ” (para. 36). Thus, policy and practices in aged and dementia care need to acknowledge the disadvantage experienced by the majority of the workforce, and make appropriate policies that attempt to reduce this disadvantage for workers. These may include prioritising work-life balance practices, providing financial support for further education, access to quality supervision and opportunities to establish professional networks where workers can seek social interaction and support.

Funding for care services and research in dementia are much lower than for other health conditions. While dementia is an international health priority and economic costs of care have been found to be the highest for dementia well above cancer, stroke and heart disease, dementia research remains comparatively less funded than other areas of health. For example, in the United Kingdom, government and charitable spending on dementia research is 12 times lower than on cancer research (Luengo-Fernandez et al., 2010). While there is disparity in funding for research across the health conditions, there is also inequality of funding distribution within dementia research, particularly in the United States. Ballenger (2008) suggests that in the United States research efforts for prevention or cure of dementia have been better funded than policies to support patients and caregivers.

In Australia, there have been recent government announcements on aged care reform with an increase to funding (e.g., Living Longer. Living Better, \$3.7 billion over five years; DoHA, 2012). Workforce development of the aged care

sector was championed as one of the priorities of the reform with a \$1.2 billion allocation, however, little details on the extent this will focus on the community-based dementia workforce were published. While this funding is mainly aimed at supporting service delivery, funding for research falls within “consumer support and research” and has a general aged care focus (\$9.1 million). Overall, this commitment is substantial. However, research is the third lowest funded area within the reform. In addition, the allocation of this funding is dependent upon the current government remaining in power after the next election. In the recent past, Australia has placed its lowest aged care funding priority on research and strengthening of care services (UN, 2011), while most funding was allocated to pensions, affordable health care schemes and long-term care. In a climate where economic expenditure is in the forefront of leaders’ minds, providing details of a targeted direction for service providers and organisations to manage resource problems that are based in sound scientific research is likely to contribute to an expedient way to focus limited resources. Thus, policy makers need improved funding for dementia care in relation to service delivery, as well as increasing the priority on research that informs evidence-based best practice and workforce development.

Recommendations

The following six recommendations have been informed by an integration of information collected from the empirical findings of the current series of studies. The purpose of providing recommendations is to improve future research and inform service providers on ways to overcome recruitment and retention issues. Further, these recommendations may inform policy makers on approaches to capacity building for dementia care. The recommendations focus on strategies that

aim to develop and strengthen the workforce and subsequent provided services. Overall, the recommendations are broad in nature. However, the third and fourth recommendations provide specific detail on potential workforce education and training, and organisational support initiatives.

1. Increase funding for dementia care and research

Funding for dementia research must be given priority. While dementia is an international health priority and economic costs of care have been found to be the highest for dementia, well above cancer, stroke and heart disease, dementia research remains comparatively less funded than other areas of health. While research on best practice for dementia care have been established these are not employed in the workplace. Thus, research funding should include a significant focus on translation science in dementia care. There is also a need to prioritising funding in workforce development and capacity building research in dementia care.

2. Increase quality in research and evaluation for workforce development

There is a need to prioritise and encourage the development of excellence in dementia care research, particularly for workforce development. Methodological weakness in studies must be overcome by a focus on the connections between theory and practice, the use of well validated measures and rigorous scientific design (e.g., RCTs). Increasing a focus on community-based dementia care and high quality studies is a priority. This will advance the field and help to establish best practice principles for workforce development and capacity building in dementia care.

3. Improve education and training in dementia care

It is necessary to improve training in dementia, so that a skilled and specialised workforce can meet patient and carer needs and be prepared for the

dementia epidemic. Training in dementia care needs to be well validated through evaluation of interventions that follow a base in theory, and review resilience and capacity building factors that include both a focus on worker development and organisational culture. A national overhaul of the current training programs in light of care standards is necessary to ensure quality and standardisation. Training in dementia care needs to be comprehensive and detail strategies to effectively manage the complex array of symptoms associated with the disease. Training should consider topics wider than dementia education. Topics in a comprehensive training intervention may include clarification on work roles, knowledge of dementia and behavioural management strategies, as well as worker individual stress management, emotional regulation, ethical issues, and managing relationships. Topics may also address cultural diversity, younger onset dementia and people in rural and remote areas. A leadership and mentorship focus for senior worker development is necessary. Training may need to include how to collaborate with other health professionals and knowledge of other services for people with dementia to allow for better referral and co-operation between services for seamless delivery for patients and carers. Higher education should focus on dementia within existing professional courses and to establish new scientist-practitioner focused professionals for dementia care studies, such as the approach taken by Bradford University in the United Kingdom. Training may extend to also include a wider approach than attending workshops and courses, and may need to alter to develop more cohesion across health care and support services. This may include the development of dementia specific networks providing the potential for the development of case collaboration and care.

4. Improve organisational support for the workforce

Providing organisational support to workers is necessary to improve retention and recruitment, and maintain resilience in the workforce. There are several ways this can be done. Providing increases in pay and improvements in employment conditions will show workers they are valued. Creating opportunities to establish professional networks where workers can seek social interaction and build a collaborative approach to learning will contribute to the workforce feeling supported. Developing career pathways that include financial support for further education and access to quality supervision will raise the prestige of care work and enhance workers' skills. Ensuring employees have work-life balance will improve the image of dementia care and may attract new employees. In addition, providing orientation and mentorship programs will help new workers to adjust quickly to the high demands work environment. Providing incentives for additional shifts and acknowledgement of good work will show workers' efforts are valued. Further, consulting with employees about the organisations' present and future agenda is likely to lead to a productive workplace culture, where workers will accept additional demands to manage the challenges of the future.

5. Encourage establishment of professional bodies

There is a lack of regulation, accreditation and professional guiding bodies to enforce and provide incentive for participation in training and workforce development. Thus, organisational systems and governing bodies need to be established to support workforce development by setting standards of education and training specific to dementia. This may also include providing networks that promote excellence in care where there is a focus on translation of evidence-based research to improve quality within aged and dementia care services.

Independent professional bodies are needed to represent; a) the worker (career development, mentorship, collegial social networks); b) protect and advocate on behalf of the consumer; and c) uphold standards of service delivery by care providers and offer resources for management.

6. Encourage a multi-discipline focus

A comprehensive approach to capacity building is required that not only improves workforce productivity and commitment, but also raises community awareness to reduce stigma and barriers of access to care. Implementation success may be improved by a multi-discipline focus and this approach may bring forth advancements in the field and facilitate translation processes. A multi-discipline approach where strengths from each field collectively inform each discipline and in turn combine for the benefit of dementia care is likely to encourage cohesion where consistency and continuity are prioritised for patients and carers.

Conclusion

The aim of the thesis was to broaden the understanding of capacity building for dementia care, in order to develop a synthesis of ideas and recommendations that aim to improve service delivery for people with dementia. The aim and objectives of the research were met by an appraisal of the nature of the ageing population and dementia care services, as well as empirical studies on workforce development factors. Capacity building strategies for dementia care were highlighted by the empirical studies and informed recommendations that encourage workforce preparedness to cope with the dementia epidemic. The challenge of translating capacity building strategies was discussed to ultimately improve service delivery for people with dementia and their carers. While the findings were based in the Australian context, it is envisaged that the approaches discussed and presented

within the current investigation can be applied to workforces internationally. The thesis expanded the view of capacity building to include both intrapersonal and organisational factors for dementia focused training and workforce development and resilience. In this way, the findings of the thesis offer a significant contribution to the area of capacity building for health and dementia care services.

In summary, workforce development and capacity building research for community-based dementia care is underfunded, has a dearth in methodological quality and there are risks of premature action on knowledge translation into practice. Worldwide community-based dementia care workforces experience disadvantage and are undervalued. In addition, recruitment and retention concerns exist in this majority female workforce. The investigation supported the international trends but found a resilient workforce. Social interaction in the form of occupational communion was found to be a reason for attraction to the job, and important for coping with high job demands. Organisational support may reduce the likelihood that dementia care workers will resign, especially when applied early in the career trajectory. There are two agendas which may assist capacity building for the dementia care workforce. The first is formal training that is evidence-based and focuses on worker and organisational change. The second is a system that supports the development of a professional identity for the dementia care workforce.

Capacity building and resilience for the dementia care workforce is vital if the image and quality of dementia care are to improve. Dementia care work is too often forgotten and given a low priority. Attracting and retaining committed workers will be less problematic once society prevails over the stigma of dementia. A focus on excellence in dementia care research and translation that is multi-

disciplinary may help reduce stigma and promote a swell of distinction within an underprivileged area. When dementia care workers are provided with affirming support from organisations and health systems that show they are valued and supported, it will be easier to recruit and retain a resilient workforce. Once there are firm foundations of evidence-based practice for capacity building in dementia care, organisations will be much closer to being prepared to cope effectively with care demands associated with the growth of dementia in the community. The findings of the thesis suggest that the essence of workforce challenges are derived from societal and cultural barriers, such as a way of thinking about dementia and aged care, that need to be overcome. As a final statement, (a quote by a female worker) summarises the common experience amongst the dementia care workforce “it’s a lovely job, but it is undervalued”.

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Appendix A

Information and Consent Forms (Study 2)



A project for workers who care for people with dementia living in the community

INFORMATION SHEET

What is the purpose of this research?

Little is known about community care workers' thoughts about their jobs, workplaces and caring for people with dementia. The project aims to explore workers ideas about future care and the workplace.

What will you be asked to do?

If you choose to participate, you will be asked to complete:

- a) a brief interview (30min) about your impressions of your job, training experience and opinion of how dementia care work might evolve or change in the future, which will be audio taped if you give permission, and
- b) a questionnaire booklet about your work and workplace support. You can choose to complete this as an online internet survey or have the booklet posted to your nominated address.

How will your personal information be treated?

All information obtained in this study will be used for research purposes only. Your work manager will not be informed of your participation in the project. Audio taped interviews will be transcribed and analysed later on. All information will remain confidential and be kept in a locked filing cabinet with access only by authorised research team members. Questionnaires and audio tapes will be destroyed 5 years after the research is published. No information identifying individual participants will be used in publications arising from the research.

Freedom to refuse or withdraw.

Participation is entirely voluntary and you are free to withdraw at any time without having to explain why. If you decide to withdraw from the research, there will be no negative affect at your place of work or on your legal rights. You may also withdraw any information about yourself that was collected.

Who is invited to participate?

Workers who care for people with dementia living in the community, as part of their job are invited to participate. Workers will be employed in a community service and work in the person with dementia's home and/or complete home visits. The brief interview is held at the UTAS Psychology Research Centre, Hobart Campus, Sandy Bay, or if unable to attend will take place over the telephone.

What do you get out of being involved?

Your participation in the project will improve knowledge about the types of support for workers and workplaces in dementia care. Information collected will help identify strategies to enhance worker roles and workplace organisation. There is no monetary reward for your participation.

Contact person

If you have questions about this research you can contact Kate Murray on (03) 6226 2576. A summary of the findings will be available after February 2012 on the following website; www.work4dementia.com

Concerns or complaints

This research has received approval from the Human Research Ethics Committee (Tasmania) Network (H0010984). If you have any concerns of an ethical nature or complaints about the manner in which the project is conducted, you may contact the Executive Officer of the Human Research Ethics Committee (Tasmania) Network on (03) 6226 7479 or human.ethics@utas.edu.au.

Who are the researchers conducting this study?

Chief Investigator: Dr Jenn Scott^{1,2}

Co-Investigators: Dr Christine Stirling², Dr Angela Martin³, Prof Andrew Robinson²
& Ms Kate Murray^{1,2}

¹*School of Psychology, UTAS,* ²*Wicking Dementia Research and Education Centre (WDREC),* ³*School of Business, UTAS.*

Dr Jenn Scott
Chief Investigator

Ms Kate Murray
Co-Investigator



The work4dementia project is part of Ms Kate Murray's PhD. Kate's candidature is sponsored by TIME for Dementia, the Tasmania and Victoria Dementia Training Study Centre, WDREC & UTAS.

The project Steering Committee comprises representatives from Home and Community Care (HACC) Department of Health and Human Services, Tasmania and the Tasmanian branches of; Alzheimer's Australia, Carers Australia, and the Commonwealth Respite and Carelink Centre.

Appendix B

Socio-Demographic Intake Interview (Study 2)



A project about workers who care for people with dementia living in the community.

Intake Form I Demographic & Occupational Details

Office Use Only				
ID	Initials	Work Type		
		Full PWD CI	½ PWD CI	< ½ PWD CI
Date	/ /	1	2	3

Participant Information

Participants Name: _____ **Date of Birth:**

_____/_____/_____

Postcode: _____

Phone: (h) _____ (w) _____ (m) _____

Occupation: _____ **Workplace:** _____

Religion: _____

What is your marital status? Are you:

Married	<input type="checkbox"/>	Divorced	<input type="checkbox"/>
Widowed	<input type="checkbox"/>	Separated	<input type="checkbox"/>
A member of an unmarried couple	<input type="checkbox"/>	Never Married	<input type="checkbox"/>

Do you have dependent children? If so how many? _____

In which country were you born?

Please specify: _____

Are you of Aboriginal or Torres Strait Islander origin?

No	<input type="checkbox"/>
Yes, Aboriginal	<input type="checkbox"/>
Yes, Torres Strait Islander	<input type="checkbox"/>

For persons of both Aboriginal and Torres Strait Islander origin, mark both 'yes' boxes.

Highest level of education completed (please circle):

Primary Yr 10 Yr11 Yr12 TAFE University

What is your annual household income from all sources?

<input type="checkbox"/> \$0-\$9,999	<input type="checkbox"/> \$25,000-\$34,999
<input type="checkbox"/> \$10,000-\$14,999	<input type="checkbox"/> \$35,000-\$49,999
<input type="checkbox"/> \$15,000-\$19,999	<input type="checkbox"/> \$50,000-\$74,999
<input type="checkbox"/> \$20,000-\$24,999	<input type="checkbox"/> \$75,000+

Have you previously been to/or are currently attending counselling or psychological support? YES / NO

If YES when _____ **, and what was this in relation to?** _____

Employment Information

On what basis are you currently employed with this organisation?

Permanent full-time / permanent part-time / casual /

Other _____ (please specify)

How long have you been employed at your current workplace?

Qualification type:

What type of training have you completed?

When?

Where?

Who delivered the training?

What type of orientation to your work did you receive when you started? (i.e. induction program)?

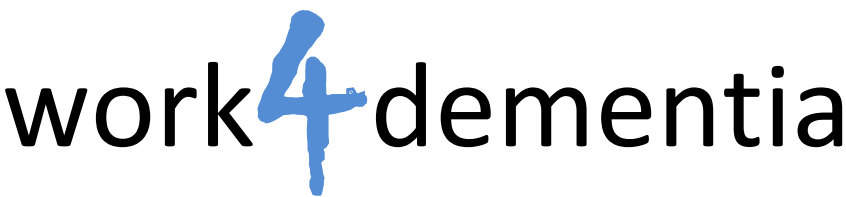
How many hours do you work in a typical week?

How many PWD would you see in a week?

Describe your ‘caseload’ / ‘clientele’ (i.e. do you also help people with disabilities?)

Appendix C

Semi-Structured Interview for Dementia Care Workers (Study 2)



A project about workers who care for people with dementia living in the community.

Semi-Structured Interview Form II
Worker Perceptions

Office Use Only				
ID	Initials	Work Type		
		Full PWD CI	½ PWD CI	< ½ PWD CI
Date	/ /	1	2	3

Roles & Duties

Describe a typical day in your job.

What do you think about the work you do?

Describe the support you receive at work? Who is it from? What type and quality of support is it?

What's the worst part of the work you do?

What's the best part of the work you do?

Future Direction of Service

Describe how you think the 'ageing crisis' and the increase in older people in the community will affect your work.

What do you think your workplace will look like in 5-10 years time?

How do you think your job will change, if at all?

If your organisation asked you to take on a new role what would you think?

Training

Do you feel supported by your organisation to complete training workshops/courses?

How are you supported by your organisation to complete training?

What do you think about the training you have done?

What type of training would you like to do?

What do you want help with in your job?

Relationship with Clients/Consumers

Describe how you get along with PWD and their family member(s).

What is important about the relationship between you and the PWD and family member?

Personal Work Goals & Management Match

Describe the goals of your workplace.

Do you agree with the goals of your workplace.

What would you say are your goals at work?

Attraction to Workplace & Future Work

What attracted you to your workplace?

Do you intend to stay at your workplace in the future? If YES, for how long?

If NO, what could keep you at your workplace?

Is there anything we haven't talked about that you would like to add?

Appendix D

Qualitative Themes and Theoretical Constructs (Study 2 - Part A)

Table 15.

Super-Ordinate Theme Occupational Communion

Constituent	Example	Theoretical construct
Caring person-job fit	“I was so excited and really passionate about the work. Yes couldn’t think of doing anything else, because I know I’m good at what I do. It comes easy and naturally” (Female; Worker 8).	Person-Job fit (P-J fit), including job/task demands and individual abilities match (Demands-Abilities job fit; Kristof-Brown et al., 2005).
Rewarding relationship with clients	“She trusts me and I think when you work in the way we do you develop a trust[ing] relationship and... they rely on you, they know that when you come, you’ll fix the problem and you’ll help do something, and that’s a good feeling” (Female; 038). “I would really miss the relationships I could build.... I’m a lot closer, I get to know them” (Female; Worker 19).	Communion (Bakan, 1966) is when individual fulfilment is experienced through relationships and a sense of belonging (Guisinger & Blatt, 1994; McAdams, 1993), including dependability.
Social need-supply job fit	“I had empty nest syndrome and this has just filled that void beautifully. I’ve got great clients. They’re just like an extended family and I’ve got people I can spoil rotten now” (Female; Worker 19). “I just like people... just interested in people... I enjoy the interaction ...” (Female; Worker 30).	P-J fit, including psychological needs and preferences /supplies match (Needs-Supply job fit; Kristof-Brown et al., 2005).
Positive emotions	“Oh look I just love it... I am so excited and really passionate about the work. Yes couldn’t think of doing anything else” (Female; Worker 19). “The best part is, yeah, just being out there and helping people. And, you know, you	Communion in terms of rewarding positive emotions though interaction with others.

Constituent	Example	Theoretical construct
	really get appreciated, which is nice. Nice positive feedback” (Female; Worker 28).	
Desire for social support	<p>“The worst part of work is not enough interaction with other [formal] carers, it’s something that we really have to organise ourselves... to be able to share the ups and downs of life and also debrief. Talk about the tricks of the trade. That would be really very useful” (Female; Worker 8).</p> <p>“The biggest resource I would like is someone else to talk to. A lot of our job is ‘make do and mend’, you know, and we have to make do with what we find” (Male; Worker 11).</p>	Communion including relationships with work colleagues. Job resources of JD-R model involving job control and feedback.
Advocacy for clients	<p>“The ability to have more money to provide them with other services, and to get them out of the house... just to be able to buy them all electric lift chairs would be wonderful. Things that will help them in their everyday life, just to make it a little bit easier... better housing” (Female; Worker 29).</p>	Communion including a desire to help others with access to resources.

Table 16.

Super-Ordinate Theme Job Demands

Constituent	Example	Theoretical construct
Practical caring role	<p>“A typical day, umm getting people up, and getting them out of bed, getting them showered and ready for the day” (Female; Worker 6).</p> <p>“...especially with the dementia... you have to think on your feet. If it doesn’t succeed once, you have to say it in a different way...It’s a real challenge” (Female; Worker 26).</p>	Job demands of the JD-R model by Demerouti et al. (2001) including physical workload, time pressure and shift work.
Working alone can be a downside	“you can feel very isolated, when you are out there working alone” (Female; Worker 3)	Job demands of the JD-R model by Demerouti et al. (2001) including physical environment.
Working with family members is almost always fine	“The family, it’s quite an important relationship, mutually. I need to talk to them, and they seem to need to talk to me. You can also get into tricky situations when a son and daughter are having a disagreement when talking to me, and try and get me on side” (Female; Worker 10).	Job demands of the JD-R model by Demerouti et al. (2001) including recipient contact.
Blurred boundaries	“A lot of your role is very unofficial, and you have to bend the boundaries at times...The hardest thing is making sure it’s a professional relationship... so you take a step back. I still care, but, I know it sounds terrible, but I can’t do my job if I care too much” (Male; Worker 11).	Job demands of the JD-R model by Demerouti et al. (2001) including recipient contact.
Humanity and helping skills	<p>“Being open and non-judgmental is important” (Female; Worker 3).</p> <p>“I also had to prepare myself to be extraordinarily patient...” (Female; 18).</p> <p>“Always listen and watch, you have to be alert the whole time with dementia clients, you can’t slacken off, because that’s when you miss things” (Female; Worker 7).</p>	Egan’s (1998) helping skills

Constituent	Example	Theoretical construct
Dealing with loss	“Working with dementia people, yeah, it can become very challenging and very sad at the same time” (Female; Worker 40)	Job demands part of the JD-R model by Demerouti et al. (2001) including recipient contact.
Emotional labour	“To work with people with dementia, emotionally it’s very draining” (Female; 23). “They know a lot more than you do as far as life experiences go. A lot of them like to chat about the war. It might sound boring as all hell to you, but at least look like you’re interested. You know, because that may be the highlight of their day” (Female; Worker 12).	Emotional labour is the regulation of emotional expressions and feelings as part of paid work role, which occurs when expected workplace emotions cannot be naturally felt or displayed, and is routinely performed using surface acting and deep acting (Hochschild, 1983).

Table 17.

Super-Ordinate Theme Job Resources

Constituent Sub-ordinate	Example	Theoretical construct
Attracted to job	“The good thing about community work is the flexibility with children. You can pick what hours you want to work and they’re not always long shifts” (Female; Worker 17).	Work-life balance (Kalliath & Brough, 2008).
Past caring experience	“Years ago my mother did voluntary work for people with impaired sight, and she also did meals on wheels, and she often talked about, how hard it was but also how much she gained from it. Also my brother was mentally disabled, so I’m just experienced with, those kind of situations around me I suppose. It just felt natural to move into that area. (Male; Worker 20).	Self-efficacy and mastery (Bandura, 1986)
Sound perceived organisational support	“I know at work, when it comes to personal matters and stuff like that, they’re brilliant. You go to them, you’ve got a problem, you need time off, anything like that... they’ve got to look after you the best that they can so we can look after other people” (Female; Worker 19).	Perceived organisational support (POS; Rhoades & Eisenberger, 2002).
Good person-organisation fit	“... I think my workplaces’ goals and organisations pretty much align with mine, or I wouldn’t be working for them” (Female; Worker 18).	Person - organisation fit (P-O fit; Kristof, 1996).
Strong organisational commitment	“They’ve [the organisation] been good to me. You know, if they look after me, I’m going to look after them, so. They’ve done the right thing by me, so I’m going to look after them” (Female; Worker 19).	POS including continuance commitment (Rhoades & Eisenberger, 2002).
Sound preparedness	“I just think it will be more, um full on.... There will be need for my services and what I do ten-fold to what it is now. And whether or not you can find people who want to do that is the thing...I think in 5 or 10 years time you are going to find you have more	Awareness, self-efficacy (Bandura, 1986)

Constituent Sub-ordinate	Example	Theoretical construct
	demented people and you will need to have more people skilled in therapies to deal with demented people” (Male; Worker 4).	
Satisfied with training	<p>“The training’s really pretty good...Oh it [the conference] was brilliant. It was a real eye opener, because some of the people who were talking were from worldwide. Just amazing to here the stats on it” (Female; Worker 7).</p> <p>“It’s all very practical” (Male; Worker 11).</p>	<p>Job resource of JD-R model including participation.</p> <p>Self-efficacy and mastery (Bandura, 1986).</p>
Leadership is fine most of the time	<p>“[supervisors’ support] is not always good – most of the time it’s fine” (Female; Worker 17).</p>	Job resource of JD-R model including supervisor support.
Undervalued / poor pay and conditions	<p>“I don’t believe we are highly recognised or paid enough for what we do” (Female; Worker 6).</p>	Job resource of JD-R model including job security.

Appendix E

Informal Dementia Carers Handout (Study 3)

The Commonwealth Respite & Carelink Centre, Australian Government presents
Carers 1st

Staying Out In Front – Now & Into the Future
25th March 2010, Tattersall's Park Function Centre

What are your support needs? Workshop Handout

What is your age group?

Up to 21 ☐ 21-34 ☐ 35-49 ☐ 50-64 ☐ Over 65 ☐

Who do you care for?

Wife	<input type="checkbox"/>	Father	<input type="checkbox"/>	Brother	<input type="checkbox"/>	Friend	<input type="checkbox"/>
Husband	<input type="checkbox"/>	Son	<input type="checkbox"/>	Sister	<input type="checkbox"/>	Other	<input type="checkbox"/>
Mother	<input type="checkbox"/>	Daughter	<input type="checkbox"/>	Relative	<input type="checkbox"/>	Please specify: _____	

How satisfied are you with the support you receive? *Please circle the number* that best describes your confidence.

Not satisfied						Extremely satisfied
0	1	2	3	4	5	6

Describe what you think are carers' unmet needs for support in their roles.

What are the barriers to meeting carers needs?

What are your views on support worker attitudes, skills & knowledge?

What do you think would improve services?

How confident are you, you can sit down with the care worker and make a care plan. *Please circle the number* that best describes your confidence.

Not confident at all

Extremely confident

0

1

2

3

4

5

6

Appendix F

Publication from Chapter Four

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Reproduction of CHAPTER 4 – published article

A Systematic Review of Dementia Training Interventions Targeting Worker and Organisational Outcomes (Study 1)

Published as :

Elliott, K.-E. J., Scott, J. L., Stirling, C. M., Martin, A., Robinson, A. L., 2012. Building capacity and resilience in the dementia care workforce: a systematic review of interventions targeting worker and organizational outcomes, *International psychogeriatrics*, 24(6), 882-894

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